

DIGITAL SELF-HARM: IMPLICATIONS OF EATING DISORDERED BEHAVIORS ONLINE

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DIGITAL SELF-HARM: IMPLICATIONS OF EATING DISORDERED BEHAVIORS ONLINE

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I dedicate this dissertation to my family, Belinda, David and Joshua Pater for your
continued love and support.

And to my first academic mentor, Dr. Jennie Lincoln, for changing the trajectory of my
life.

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LIST OF SYMBOLS AND ABBREVIATIONS

ADHD	Attention Deficit/Hyperactivity Disorder
AI	Artificial Intelligence
AN	Anorexia Nervosa
API	Application Programming Interface
AR	Augmented Reality
ASIST	Applied Suicide Intervention Skills Training
BN	Bulimia Nervosa
CBT	Cognitive Behavioral Therapy
CSCW	Computer Supported Cooperative Work
CT	Cultivation Theory
DSM	Diagnostic and Statistical Manual of Mental Disorders
EAT-26	Eating Attitudes Test
ED	Eating Disorder
EDE-Q	Eating Disorder Examination Questionnaire
FSC	Farrington Specialty Counseling
GDPR	General Data Protection Regulation
HCI	Human-Computer Interaction
HIPAA	Health Insurance Portability and Accountability Act of 1996
ICT	Information Communication Technology
LGBTQ	Lesbian, Gay, Bi-sexual, Transexual, Queer
LIWC	Linguistic Inquiry and Word Count
NSSI	Non-Suicidal Self-Injury

OCD	Obsessive Compulsive Disorder
OSFED	Other Specified Feeding and Eating Disorders
PBH	Parkview Behavioral Health
PHI	Patient Health Information
PHQ-4	Patient Health Questionnaire
POV	Point of View
PPG	Parkview Physicians Group
PRC	Parkview Research Center
PRO-ED	Pro-Eating Disorder
PTSD	Post-Traumatic Stress Disorder
QPR	Question. Persuade. Report
SCT	Social Cognitive Theory
TOS	Terms of Service
VR	Virtual Reality

SUMMARY

It is estimated that 10%-20% of the US population will struggle with an eating disorder at some point in their lifetime [258]. Eating disorders is a complex set of psychiatric disorders that, regardless of classification, share several key characteristics including a disturbance of eating habits or weight-control behaviors and a clinically significant impairment of physical health or psychosocial functioning [3]. Self-image and identity are interwoven aspects of ED symptomology [86] and online spaces have been found to have impact on body image and eating pathology [217], thus highlighting the need for a deeper understanding of how ED patients use these online tools throughout their disease journey.

A core tenant of social computing research focuses on understanding behaviors of people using online spaces [19,148,267] and how the design [21,190,253] and policies [40,191] of these spaces impact user behavior. This growing research domain is quite diverse. In the last decade, attention on how the social media landscape impacts mental health has drastically increased as the volume of users and the time spent within these online spaces has exponentially increased. The ubiquitous nature of mobile computing technologies and the rise of social media platforms integration into these technologies has given individuals unprecedented access to a diverse set of people and ideas. This ubiquity is so complete that 27% the most recent generation of users estimate being continuously connected to the internet [232]. Taking these factors into consideration, a need exists to understand how people with eating disorders use social technologies to support their disease states and what this online use looks like at a network level.

In this dissertation I seek to connect a person's digital activity to their physical health condition, an eating disorder. I ground my research in a quantitative and qualitative assessment of a specific population and condition: patients with eating disorders and the impacts of their online activities on their disease. I want to understand how social media use impacts a person's active disease state. How are eating disorders characterized online? Should online activities that support active disease states be classified as a form of digital self-harm? What can be learned from assessing a diagnosed patient's social media streams leading up to the beginning of their recovery journey?

Over the last several years, I have analyzed eating disorder focused social media content across multiple platforms. Using this knowledge, I put forth an expanded concept of digital self-harm, grounding it within a clinical context. Finally, I worked with a set of clinicians and patients to understand the role that social media and other social technologies played in their active eating disordered activities and behaviors, thus testing my thoughts on digital self-harm with a patient population.

In this dissertation, I test the following thesis: *Patients with a clinically diagnosed eating disorder who actively use social technologies will use social media platforms as a process of engaging with digital self-harm activities.* My research addresses the following research questions:

1. What is the presentation and characterizations of eating disordered activities online?
2. What are the online behaviors of people clinically diagnosed with an eating disorder?

3. How might evidence of online eating disordered behaviors best be integrated into clinical treatment?

This work makes contributions to the Human-Centered Computing field through the identification and characterization of mental health issues across multiple online platforms. Additionally, it highlights the potential bias and ethical issues of these practices. To the health informatics field, this work highlights the direct connections of the use of social technologies and exacerbated disease states and the complexities of integrating this knowledge into clinical practice.

CHAPTER 1. INTRODUCTION

A core tenant of social computing research focuses on understanding behaviors of people using online spaces [19,148,267] and how the design [21,190,253] and policies [40,191] of these spaces impact user behavior. This growing research domain is quite diverse. In the last decade, attention on how the social media landscape impacts mental health has drastically increased as the volume of users and the time spent within these online spaces has exponentially increased. The ubiquitous nature of mobile computing technologies and the rise of social media platforms integration into these technologies has given individuals unprecedented access to a diverse set of people and ideas. This ubiquity is so complete that 27% the most recent generation of users estimate being continuously connected to the internet [232].

A preponderance of this use is focused on connecting people to other individuals and to content that support them in positive aspects, as demonstrated through the vast resources focused on domains from informal [61,94] and formal education [44,102], to support for chronic illnesses [121,221] and rare diseases [147,223], to organizing political movements [63,271]. Research from the initial days of modern social media found indirect relations between the frequency of platform use and the impacts it had on their sense of self [252]. As these tools grew in sophistication so did people's use of these tools as part of their lived experience/how they connected to their social life. Now that large components of social and emotional connections being documented in public spaces, new complications arise like context collapse between our social networks [150,256], oversharing of our personal

lives [4], and new types of behavioral issues connected to and predicated on the unhealthy use of these technologies [65,88,199,266].

An additional complexity to understanding the connections between online activities and disease states is understanding how representative an individual's online behavior is of their offline being. Using Goffman's dramaturgical approach, it allows one to contextualize how an individual presents themselves as it is situated culturally through shared values, norms, and beliefs [97]. This approach is frequently used as a foil for understanding online presentations of self [117] with respect to ground social media and identify performance [26,27,247], privacy [141], and impression management [156]. Social technologies allow people to document their "performances", tag them for easier identification and signaling, and allow them to be searched for future, asynchronous engagement by others in the community.

The rise in mental health issues, specifically eating disorders, is another motivation for understanding how social technologies are being used. It is estimated that 10%-20% of the US population will struggle with this set of disorders at some point in their lifetime [258]. Eating disorders are a complex set of psychiatric disorders that, regardless of classification, share several key characteristics including a disturbance of eating habits or weight-control behaviors and a clinically significant impairment of physical health or psychosocial functioning [3]. Self-image and identity are interwoven aspects of ED symptomology [86] and online spaces have been found to have impact on body image and eating pathology [217], thus highlighting the need for a deeper understanding of how ED patients use these online tools throughout their disease journey.

To address these issues, I designed a set of research studies that would allow me to connect the digital to the physical as it relates to eating disorders. To do so, I characterized how eating disorders are presented within the current generation of social media platforms and then assess if these online behaviors and activities are present within a population of individuals who have been clinically diagnosed with an eating disorder, bridging our general knowledge of disease-related activities with specific clinical markers and patient data. I test the hypothesis: *patients with a clinically diagnosed eating disorder who actively use social technologies will use social media platforms as a process of engaging with digital self-harm activities.*

Through this research, I advance the field's understanding of the impact of using social technologies on the physical manifestation of mental health issues, like eating disorders. My research addresses the following research questions:

1) What is the presentation and characterizations of eating disordered activities online? The social computing field has increased the levels of research focused on understanding the general overview of these behaviors online and how to detect content related to eating disorders within a specific social media platform. In Chapter 3, I describe the use of these detection methodologies to identify a wide array of online eating disorder content and in Chapter 5, I discuss the use of this approach to collect content from across multiple platforms and the various types of media archetypes that distilled from my qualitative assessment of the content collected.

2) What are the online behaviors of people clinically diagnosed with an eating disorder? Within social computing research, detection and characterization of online

activities and behaviors within the mental health space typically stop short of assessing if these patterns are present within a clinical population as this knowledge base is most always built upon the use of public datasets. In Chapter 6, I discuss the formulation of the partnership with the Parkview Health network which gave us access to a patient population. Chapter 7 reviews the outcomes of a multi-tiered case study where patients reflected on the disease-related impacts of using technology to support their eating disordered behaviors in addition to an analysis of their social media data for the 18 months leading up to their initial treatment.

3) How might evidence of online eating disordered behaviors best be integrated into clinical treatment? There are no diagnostic tools used within the treatment of an eating disorder that assesses the patient's use of technology or the impact that technology has on their disease. In Chapter 6, I review the outcomes of an interview study with clinical providers who treat patients with eating disorders to unpack if patients discuss technology use with them, if they do what type of use is the most common, and how they handle these discussions. Further, I explore the providers' perceptions of using social media within the clinical context and what are the benefits and challenges associated with the integration of this type of patient data within the clinical context.

Table 1-1 Overview of dissertation research questions, methods, and data

Research Question	Method	Data
What is the presentation and characterization of eating disordered activities online [40,193,195]?	Quantitative assessment of online content related to eating disorders (ED) on Instagram.	434,000 posts
	Qualitative assessment of ED content across platforms.	575 posts
	Qualitative assessment of male-focused ED-content across platforms.	323 posts
What are the online behaviors of people clinically diagnosed with an eating disorder [194]?	Qualitative and quantitative social media analysis of 18-months of Facebook and Instagram data of clinically diagnosed patients	3 patients
How might evidence of online eating disordered behaviors best be integrated into clinical treatment [197]?	Thematic analysis of interviews with healthcare providers who treat patients with eating disorders	14 healthcare providers

1.1 Healthcare Setting

All participant-related research described in this dissertation took place in Fort Wayne, IN in collaboration with the Parkview Health System. Fort Wayne, IN is the second largest city Indiana and located in the Northwest region of the state, with a population of

approximately 268,000¹. The median income in Fort Wayne is \$45,853 and approximately 17.8% of the population live at or below the poverty line. The population is 74.2% Caucasian, 15.0% African American, 8.7% Hispanic, and 4.3% Asian. Parkview Health serves a population of close to 900,000 people in the northeast Indiana and northwest Ohio region.

The Parkview Health system is comprised of over 12,000 employees working at nine hospitals, the Parkview Cancer Institute, the Parkview Heart Institute, and the Parkview Physicians Group. Parkview Health is a not-for-profit health, community-based health system. Parkview Health is recognized by Truven Health Analytics/IBM Watson Health as one of the top 15 health systems in the country. Additionally, the system has an embedded research arm, the Parkview Research Center (PRC), which has completed more than 300 clinical studies.

Parkview has a commitment to the system and the community to provide comprehensive mental health services: they provide inpatient, outpatient, and partial hospitalization programs and has northeast Indiana's only inpatient mental health services for children and adolescents. Parkview Behavioral Health recently formed a partnership with the Alliance for Eating Disorders to offer free support groups at the Parkview main campus. In addition to working with clinicians at Parkview, the research partnered with Farrington Specialty Counseling (FSC) in Fort Wayne, IN. This center is solely focused on the treatment of eating disorders, compulsive exercise and body image issues in addition to any comorbidities like anxiety, depression, or trauma.

¹ United States Census Bureau Quick Facts

1.2 Overview

This dissertation is organized as follows:

In Chapter 2, I describe related work that provides a foundation for my research. My work is motivated by research focused on the clinical concept of an eating disorder, online communities, patterns of teen and young adult technology use, and theoretical models of behavior change. I review the research from each of these domains and briefly state how my research expands this knowledge base.

In Chapter 3, I explore the concept of Digital Self-Harm (DSH). A concept that I expanded to encompass the symptomatology associated with clinical definition of self-harm, DSH anchors the research that comprises this dissertation.

In Chapter 4, I describe the challenges of defining DSH in terms of eating disorders within online spaces. I review an exploratory study I conducted in Instagram – a popular social media platform. I present the iterative, qualitative process of uncovering ED-related content and how the lexical components of this content vary.

In Chapter 5, I describe two formative studies focused on characterizing the online presentation of ED content across several online communities. First, I present an initial characterization that used clinically- relevant terminology to classify ED content. I then describe a study to understand the differences and similarities of male-related ED content in online spaces that replicated the first study, yet used more colloquial and male-related terminology to seed the data collection.

In Chapter 6, I discuss the clinical understanding of digital self-harm behaviors. First I describe the impetus for partnering with a health system and the health system collaboration with PRC and Parkview clinicians. I worked with the Parkview team to map the standard network of care for patients with eating disorders in their community. Next, I describe an interview study I conducted with the various points of care for patients with eating disorders within the community. I present how these providers handled discussions of technology use in relation to patients in treatment for an eating disorder(s).

In Chapter 7, I discuss a case study connecting aspects of DSH with a clinically diagnosed population. First I present a multi-faceted case study with 3 patients that connected various health and technology use surveys, in-depth interview, and an analysis of patient social media data leading up to their initial point of recovery. Second, I present the outcomes of this study and implications for design, both technical and policy related.

In Chapter 8, I reflect on the body of this dissertation research. I describe what I have learned about digital self-harm. In doing so, I describe the characterization of eating disorder activity and behavior online, how patients internalize digital self-harm, and challenges associated with generalizing mental health states based on public social media data.

In Chapter 9, I review the various contributions that emerged from this research and offer insights for future research in this domain. These include policies and the ethics of characterizing online mental health activities, the integration of online data into clinical practice, the role of social media platforms as mental health interventionists and the expansion of the digital self-harm concept.

CHAPTER 2. RELATED WORK

2.1 Motivation

It is estimated that there at least 20 million women and 10 million men in the United States suffer from an eating disorder at some point in their lifetime [258]. Despite the commonality of these health issues, eating disorders (EDs) continue to be ignored and overlooked at the state and national levels [276]. Healthcare professionals and politicians have begun to recognize the impact of eating disorders on the populace as a growing public health threat [276]. Anorexia has the highest mortality rate of any psychiatric disorder [10]. A woman 15-24 years old with anorexia is 12 times more likely to die than a women without anorexia, and the frequency of suicide is 75 times greater than a young woman without an eating disorder [238].

Understanding the context of eating disordered behaviors and activities online is not new - as early as 2001, popular news outlets began reporting on the presence of the alternative communities of anorexic people online [212]. With increasing access to new media platforms, individuals with eating disorders no longer needed to meet up with other individuals with ED through in-person connections, at clinics, or at hospitals, but instead were able to establish and support thriving pro-ED communities online [23]. Pro-ED communities are communities that contextualize EDs as a valid, normal lifestyle and not a medical condition [24]. Over the years, these communities have taken many forms – individual websites [24,226], blogs [85], bulletin boards [28,93], and decentralized communities on social media [45,125,154,259].

2.2 Eating Disorders

Eating disorders are a group of psychiatric disorders where a patient becomes obsessed with food intake, weight, and perceived body image (both internal and external) [275]. While Anorexia Nervosa and Bulimia Nervosa are the two of the most popularly known eating disorders, they are not the most common ED-related illnesses – the most common is “Other Specified Feeding and Eating Disorders” [3]. Regardless of classification, all eating disorders are defined by three key characteristics [3,77]:

- A disturbance of eating habits or weight-control behaviors
- A clinically significant impairment of physical health or psychosocial functioning
- The behavioral disturbance is not secondary to any general medical disorder or to any other psychiatric condition

The motivations driving these behaviors are often complex to unpack – yet at its core, they focus on individuals who view nutrition and the process of eating as a mechanism to solve or camouflage problems that seem insurmountable or insoluble [29] or a way of dealing with levels of self-worth [277]. While these diseases share commonalities, they also have distinguishing characteristics specific to the individual illnesses. Below I briefly describe the three most common classifications of eating disorders – Anorexia Nervosa (AN), Bulimia Nervosa (BN), and OSFED – and detail their defining characteristics.

The age at onset for eating disorders has classically been discussed as a disease of adolescence and young adulthood [107], yet are present at all age ranges [140,158,203]. A recent study has validated onset during adolescence: AN’s mean onset of 18.0 years and BN’s mean onset of 18.2 years [257] with OSFED’s onset also at 18 [178]. The average range of onset for all three types is between 14 years and 25 years.

2.2.1 *Anorexia Nervosa (AN)*

Anorexia Nervosa has four essential diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) [3]:

- Refusal to maintain body weight over minimum expected for age and height
- Intense fear of gaining weight
- Disturbance in the experience of body weight and shape, undue influence of weight and shape on self-evaluation, or denial of seriousness of low body weight
- Amenorrhea (irregular menstruation cycles)

2.2.2 *Bulimia Nervosa (BN)*

Bulimia Nervosa also has four essential diagnostic criteria outlined in the DSM [3]:

- Recurrent episodes of binge eating and an awareness of loss of control during the bingeing
- Recurrent inappropriate compensatory behavior to prevent weight gain (e.g., self-induced vomiting, laxatives, excessive exercise or fasting)
- Self-evaluation unduly influenced by body shape and weight
- Binge-eating and compensatory behaviors occurring twice a week for three months

2.2.3 *Other Specified Feeding and Eating Disorders (OSFED)*

OSFED is a category of eating disorders that does not meet criteria for either Anorexia or Bulimia. It has six criteria outlined in the DSM [3]:

- For females, all criteria for Anorexia Nervosa are met except that the individual has a regular menstruation cycle
- All the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
- All the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
- The regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after eating small amounts of food)
- Repeatedly chewing and spitting out, but not swallowing, large amounts of food.

- Binge-eating disorder: recurrent episodes of binge eating not characteristically typified in Bulimia Nervosa.

OSFED should not be perceived as a less serious or less severe eating disorder. On the contrary, the only reason there is delineation between OSFED and Anorexia or Bulimia is based on the presentation seen with the eating disorder [231]. The classifications have nothing to do with severity or potential impacts of the illness on the individual

A firm understanding of what defines eating disorders and shared characteristics is a foundational element core to identifying online behaviors and activities related to eating disorders. I use this clinical foundation within the dissertation to develop a new definition of digital self-harm to inform the identification and analysis of eating disordered behaviors across online social platforms.

2.3 Online Health Communities

Health communities are a common vein of scholarship within the HCI and social computing literature. Research typically focuses on how communities can use technology to support behavior change [159], how technology mediates and fosters meaningful relationships [72], and how the technology can communicate information for deeper learning and greater understanding related to health issues [110]. These are valuable and needed research agendas. Yet, they also represent a pro-social bias within the HCI community [200]. The same mechanisms that we see in this pro-social research is often found in research that doesn't support positive health outcomes, but is inverted to promote diseased behaviors [195].

2.3.1 Eating Disorder Communities

Individuals grappling with behaviors and activities outlined above used the Internet to connect and collaborate in the sharing of best practices [93], sharing inspirational media known to the network as *thinspiration* [84], and connecting with others to support their activities in a non-judgmental manner [23]. Interactions on these platforms encourage the sharing of knowledge, attitudes, and behaviors for the disorder with the broader network to amplify the destructive impact they have on themselves [24,84]. These networks can use different technologies including bulletin boards, static websites, blogs, groups on social network sites, email listservs [23], or more recently through hashtags within social media platforms as an informal, ad-hoc network [30]. Contemporary HCI research has focused on characterizing ED activities in online spaces [40,45,84,96,183,195,240,260] and methods for the classification and prediction of EDs [37,38,260].

While a majority of literature classifies these groups of individuals as *communities*, I will refer to them as *networks* or *support networks* as to not conflate these groups with more traditional definitions of community. I use the term *support networks* not as a traditional support group seeking health, but a network supporting the actions associated with the disease. Support networks that support eating disorder activities and behaviors construct social norms and customary patterns that govern the group members' activities and perceptions of reality as reflected through the collective voice [43]. This perspective allows a focus on the exchanging of knowledge and practice through collaborative dialogue [248]. A constructivist approach to identity and network formation is critical in understanding how such a decentralized and fluid community maintains norms and a sense of presence despite hurdles like community censorship and moderation.

2.3.2 *Self-Presentation*

Online spaces allow people suffering the ability to self-disclose aspects of personal identity or behaviors associated with issues while at the same time seeking support for them. For example, participants of suicide-focused Internet forums often situate their participation as not just a “cry for help” but as part of their identity [119]. Online forums allow these identities to be tried out, expressed, and validated [119]. To engender what they hope is seen as an authentic self-presentation, participants often consider audiences when constructing their narratives about depression and how and when it started [137,138]. The use of these online forums for sharing has also been viewed as a type of identity performance; for example, in the context of self-harm, the self-harmed body becomes a site of intersecting discourses [225].

These presentations often take place in online spaces not specifically dedicated nor designed for such sensitive disclosures. Andalibi et al. looked into depression-related images and captions on Instagram and found that people often disclose personal narratives and stories, negative affect, and self-appearance concerns, and seek social contact [6]. In the context of expressions of loneliness, Kirvan-Swaine et al. found that Twitter expressions of loneliness included temporal bounding of loneliness (enduring vs. transient), the inclusion of context (social, physical, romantic, and/or somatic), and explicit interactivity within the expression (e.g. requesting engagement) [130].

Whereas online communities for eating disorders have used technologies like websites and blogs for support of active disease states in the past [84], contemporary informal networks of care use social media platforms to connect and amplify support for disease

characteristics expounded in previous section. In my research, I characterize online ED behaviors across multiple social media platforms. Further, through this work I created a taxonomy of ED related terminology that is shared publicly for use by the community.

2.4 Theoretical Models of Behavior and Behavior Change

HCI scholars leverage several theoretical frameworks to harness explanatory power and inform the design of systems because they afford researchers a richer understanding of underlying dynamics and help identify methods that researchers might use in the design of new processes, interventions, or developed systems. In this section I describe the three key theories operationalized in my research. They include Social Cognitive Theory [12], Cultivation Theory [166], and Social Support Theory [136].

2.4.1 Social Cognitive Theory

Introduced by Bandura, Social Cognitive Theory (SCT) explains individual behavior change within the context of the broader society [12]. Rooted in cognitive psychology, this theory posits that when an individual observes specific behaviors and its consequences, this past experience is then recalled informing future actions. Using SCT allows researchers to understand different social, psychological, and environmental influences on behaviors. SCT also gives explanatory power to how behavior change can be deeply influenced by one's own self-efficacy, or the belief in your ability to make substantial or lasting change [235]. This is a key factor when considering designing more targeted treatments and interventions.

Applications of SCT have extended it beyond an individual's self-efficacy to encompass social influences of in individual behavior, or collective efficacy – describing an “individual's beliefs about the ability of a group to perform concerted actions that bring desired outcomes” [153]. This evolution is important for social computing research as it gives theoretical grounding for understanding how actions within the online community impacts the individual as well as how it can be used to inform the design and analysis of persuasive systems [159].

The power of employing the SCT lens to study digital self-harm lies in its ability to analyze the impacts of accessing digital self-harm content found online. Examples of this research include understanding the influence of thinspiration and interaction online related to engaging in self-harm behaviors. SCT-influenced therapies or interventions for digital self-harm would therefore look at technology's influence on the individual. Understanding how an individual uses online platforms to access information, people, or influences related to his or her disease could give clinicians a more holistic understanding of factors influencing different presentations of self-harm.

2.4.2 Cultivation Theory

Originally developed to better understand the effects of television viewing, Cultivation Theory (CT) is a social communications theory that describes the psychosocial impacts of television use on the individual [92]. The assertion here is that over time, this media slowly begins to impact a viewers' perception of reality [91]. In this manner, Gerbner posits that the television cuts across different environments and socio-economic states, bridging divides between communities, and ultimately socializing people into specific roles and

behaviors [103]. Unlike other theories that focus on direct effects, CT – like Legitimate Peripheral Participation – underscores the types of fore that pulls an individual deeper into the medium [166].

Media can and does influence beliefs, values, and attitudes, and thus cultivation theory as strong ties into psychosocial health [108]. Because of the psychosocial nature of several co-morbid psychosocial disorders associated with self-harm disease (Anxiety, Schizophrenia, and Substance-related disorders) [127,143], CT provides theoretical links that allow researchers to explore the connections between media influences and behavioral health. CT could address is understanding the influences of “thinspiration” videos and images. Are extreme images more powerful or counterproductive? Is pervasive access the most influential feature of thinspo media?

2.4.3 Social Support Theory

Social support theory offers a theoretical lens that is useful in understanding ED networks. The theory posits that influencers in an individual’s life can provide positive social encounters and discussions that will result in changes in behavior [54]. In typical social health literature, this support is positive in nature and focused on using peer support through parents, teachers, or friends [159] to encourage behavior change that is both positive and sustained.

A contrast arises between social support’s expected outcome in traditional contexts – positive impact on an individual’s ability to cope with stress [54] – and its role in ED networks. For someone with an eating disorder, not being in complete control of caloric intake and management is a primary source of stress [55]. Social support within the lens of

an eating disorder network or group means trying to inspire yourself and others to be the “best anorexic” or “best bulimic” person you can be [215].

The integration of these three theories shaped the research design, instruments developed/used with participants, and the analysis of data throughout the various studies. The studies outlined in Chapters 4-6 will further explore the outcomes in the context of these theoretical constructs

CHAPTER 3. DEFINING DIGITAL SELF-HARM

In this chapter, I present the concept of digital self-harm for which I contributed a definition to the HCI community that is grounded in a clinical context [200]. In this contribution, I synthesized previous literature from multiple fields to explore the dynamic relationship between online, mobile, and pervasive computing practices and the growing genre of self-harm behaviors that are mediated through the use of online platforms. In addition to providing an operational definition for this concept, I connected this concept to theories salient for researching digital self-harm behaviors. Finally, I organized a research agenda focused on developing a deeper understanding of digital self-harm behaviors and the possible correlations and causation between digital self-harm and potential disease states.

3.1 Background

Self-harm, the infliction of pain or harm onto oneself [182], is a mental illness that is growing in prevalence. Examples of self-harm behaviors include restrictive and binge eating, cutting, hitting, scratching, burning, bleaching of an individual's body, and other forms of self-mutilation [131]. Prior to the Internet, individuals seeking to self-harm or seeking information related to tips and tricks, or best practices, associated with these destructive behaviors were often isolated, relegated to the fringes of society [1].

However, with greater connectivity and access provided by information and communication technologies (ICTs), these groups of like-minded individuals have created online spaces to foster and encourage self-harm behaviors and activities. This online interaction is not a new phenomenon - Usenet and bulletin boards gave power to individuals seeking to find like-minded support via the connections it established. Soon

after, chat rooms and instant messaging became a way of connecting individuals together to support one another's eating disorders [84], body dysmorphia [99], and self-mutilation [264].

3.2 Clinical Understanding of Self-Harm

Self-harm is a term commonly used to describe a set of behaviors and activities associated with individuals who cause physical pain or injury to oneself [279]. Reasons of why someone would self-harm vary. Some posit that these acts are an extreme way to cope with distressing or painful feelings [279]. Others focus on this disorder being more associated with body dysmorphic delusions [83]. The prevalence of self-harm varies by age-range. A 2014 World Health Organization Study survey found that 20% of 15 year-olds surveyed reported having self-harmed within the last 12 months [60] compared with more general population samples that found a 0.9% prevalence rate in the last 12 months [132]. Lifetime rates of populations range between 15% to 20% [218,263].

Self-harm behavior can be classified as either direct or indirect self-harm. Direct self-harm is defined as the deliberate, direct destruction or alteration of body tissue without conscious suicidal intent, but resulting in injury severe enough for tissue damage to occur [78]. Direct self-harm manifests itself in many forms including the cutting, burning, scratching, and hitting of oneself [162]. Other forms of direct self-harm include skin bleaching [42], hair-pulling [123], and the ingestion of hazardous chemicals [100]. Defining direct self-harm is linguistically challenging: it is often used interchangeably with the terms self-injury [131], self-mutilation [79], and self-wounding [241]. The unifying thread across these terms is the distinction that an individual is non-suicidal and inflicting

direct injury to their bodily tissue. In the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), non-suicidal self-injury (NSSI) is now recognized as a distinct health condition.

Indirect self-harm refers to non-suicidal behavior that results in an individual physically mistreating or abusing him or herself, yet not causing immediate direct bodily damage [234]. Examples of indirect self-harm activities include eating disorder behaviors, involvement in physically abusive relationships, prolonged substance abuse, and risky or reckless behavior [234]. The eating disorder (ED) community tends to be the most illustrative indirect self-harm community and, as such, it is where a majority of the indirect self-harm literature is focused [1,28,84,226]. Indirect self-harm does not have the same presentation as direct self-harm - it typically manifests itself as a form of expression, a way to ground oneself, and a way to feel and regain control and to punish [185]. It can also often be used as a tool or mechanism to help cope with emotional pain, intense anger and frustration [234], and can even be used by some to decrease tension [100].

3.3 Definition of Concept

In 2010, the first concept of digital self-harm was informally published and described as “teens who are self-harassing by ‘anonymously’ writing mean questions to themselves and then publicly answering them” [25]. As a response to this concept, some in the field began to describe this phenomenon as “digital Munchausen” [73]. Even recent research has not expanded beyond the scope of this initial definition [189]. While this definition is important, it neglects other types of self-inflicted harm that can take place through online spaces.

Based on the limitations of the current operational definition of digital self-harm, I purposed an expanded definition of this concept. I define *digital self-harm* as the online communication and activity that leads to, supports, or exacerbates, non-suicidal yet intentional harm or impairment of an individual's physical wellbeing [200]. By using the clinical definitions of self-harm in the previous section, the digital variant of self-harm can be extended to capture nuances specific to the online domain. Access to content, people and institutions that support or reinforce destructive, non-suicidal ideas or behaviors potentially drive the degree of impact digital self-harm has on an individual. By removing barriers of time, distance, and transience, the landscape of the Internet – be it a community, access to information, or the ability to freely express one's diseased self – creates a fertile environment for the potential deepening and strengthening of these behavioral issues within an affected individual through the sharing and reinforcement of destructive behaviors.

It is important to note that there are other forms of self-harm that are not included in the clinical definition informing this agenda. Self-injury associated with people with developmental disabilities, such as children on the autism spectrum, is an example of self-injury behaviors that is not included in the clinical classification informing this agenda. The most common forms of these behaviors include head banging, excessive self-rubbing and scratching, hand biting, and picking of the skin and/or face [67]. This type of self-injury is not included because they are often involuntary actions that are neurologically triggered by an underlying disability and not incited by activities mediated online.

Additionally, activities that focus on using online content to incite an individual to inflict pain on others are not included in this definition. The Internet has been used as a

vehicle to do just that – encourage individuals to act or behave in a manner that negatively impacts others both online and offline – in the contexts of behaviors such as terrorism, pedophilia, and racism. Thus, if the underlying cause of these behaviors is rooted within a recognized medical neurological condition, or the person targeted for injury is someone other than the perpetrating individual, that behavior is not considered an example of digital self-harm.

3.4 Examples of Digital Self-Harm

In this section, I present two examples of digital self-harm beyond the traditional definition and support the operational definition I offered in the previous section. Note: this section contains imagery from social media that individuals might find challenging or disturbing.

3.4.1 Eating Disorder (ED) Communities

ED-focused online communities are collections of websites, blogs, and social media feeds known as pro-ana (or pro-Anorexia) and pro-mia (or pro-Bulimia) [226]. ED communities promote their activities as healthy or “normal” and frame their activities as a legitimate lifestyle option [84]. These communities usually contain supportive and persuasive language, portals to share information and best practices, discussion forums, and media sharing capabilities.

ED communities are interactive in nature. They allow community members to communicate with each other and contribute to the culture of the community by sharing media, resources, and personal experiences [24,84]. Participants in ED communities often use strong and direct language to ensure the makeup of the community share similar beliefs

and traits. These communities offer a place to learn from community members away from the scrutiny of family, friends, and the medical system [171]. Below is an example of the strong language that can be found in these communities:

IF YOU WANT TO LOSE WEIGHT, GO ON A DIET FATTY. ONE IS EITHER ANA/MIA OR NOT. IT IS A GIFT AND YOU CANNOT DECIDE TO HAVE AN EATING DISORDER. SO IF YOU ARE LOOKING FOR A WAY TO LOSE WEIGHT, S-S-S-S-SORRY JUNIOR!! MOVE ON, TRY JENNY CRAIG [24].

Media sharing is an important feature in many of these online communities [195]. The ability to reinforce shared norms within the community is routinely done through the sharing of *thinspiration*, or *thinspo* for short. This blend of *thin* and *inspiration* involves the sharing of photos, videos, and prose that are intended to inspire eating disorders [142]. Figure 3-1 shows a compilation of traditional forms of thinspiration one might encounter in these online communities [195].

3.4.2 *Cutting Communities*

Online communities that support the act of cutting are also representative of destructive digital self-harm activities. Similar to pro-ana and pro-mia communities, pro-cutting communities offer a platform for the sharing of best practices and tools of the trade. Like those that participate in ED-community activities, individuals who identify with cutting communities often use specific vernacular to identify or attach themselves to the group within the larger masses. These terms include cat(scratch); cut(s)(ing)(ter); razor(s); scar(red); and selfharm(m)(mm) [195].



Figure 3-1. Examples of thinspiration media online

The intent of the individuals that use these terms can be classified as either normalizing or pathologizing [99]. Normalizing uses of these terms seek to legitimize these activities as a way of dealing with mental health issues whereas pathologizing uses are focused more on an individual's body being repulsive and the behavior is seen as morally reprehensible. This discourse is carried out through the more common text, images, and video, but also through original artwork, music and other expressive communication mediums. Figure 3-2 is an example of this discourse presented graphically through image.

These examples of eating disorder and cutting communities are illustrative and help articulate the scope of digital self-harm activities. They provide a look at how both indirect (eating disorder) and direct (cutting) self-injury behaviors are presented in online spaces. While there are several similarities between these two examples, there are also distinct differences. One distinct difference is that direct harm content tends to focus more on action-oriented activities.



Figure 3-2. Examples of cutting inspiration media online

Because of the influential and impactful nature of this type of display, these types of media serve as powerful motivators. Additionally, persistence of these exemplars online plus ease of access ensure that whenever someone needs to reconnect to the destructive and unhealthy message it reinforces, it is readily available. Research has shown ED websites may have contagion-like effects on individuals experimenting or seeking information about eating disorders before exhibiting signs and behaviors of commitment to them [24]. With respect to adolescents and eating disorders, one concern is that a relatively healthy, or at least stereotypical, desire to lose weight may lead to unintended exposure to this type of content.

3.5 Opportunities for Future Research

A corpus of research characterizing self-harm content and behavior online is evolving within the social computing and HCI space. These studies have started to examine the types of content that is shared [24,193,195], how information is shared online [84], how self-harm communities respond to moderation [40], and the ethical issues surrounding these platforms [226]. These studies have begun to expose the complexity and scope of digital self-harm within computing contexts and outline the types of activities that are found on

social media platforms and websites. This research is limited in its explanatory power because it neither connects the online activities to individuals that have a clinical diagnosis, nor does it dive into the online presentations and their influence or impact on others. While these initial research contributions are fundamental to understanding digital self-harm at a high-level, a broader research agenda should encompass understanding the design affordances associated with online interactions and the impact of these experiences in promoting, facilitating, triggering, and sustaining self-harm behaviors.

There are many unanswered questions within this research agenda. How to identify the numerous forms of self-harm within digital contexts? Can online spaces be designed in a way that is more responsive to presentations of self-harm? What are the ethical responsibilities of online communities as it relates to individual expression of self-harm and the health impacts these activities have on the community members? Research is needed to understand how scope, entrenchment, degree of severity, and other factors of self-harm are exacerbated through digital exposure. Based on my survey of relevant literature, including the clinical definition of self-harm, an initial description of some digital self-harm online activities, and a distillation of related work; in Table 3-1 I outline common digital self-harm activities that warrant further research.

Table 3-1 Future Digital Self-Harm Research

- Propagating and proselytizing “norms” that assert self-harm as a legitimate alternative lifestyle through text and media.
- Providing tools and interactive features that allow one to track self-harm activities and measure against individual and shared goals.
- Curating content to directly trigger self-harm actions.
- Providing tips for how to hide self-harm actions from offline peers and family members.
- Recruiting and motivating individuals to engage in self-harm actions.
- Recruiting individuals to participate in online community activities that increase the commitment to self-harm.
- Sending reminders or other forms of “push” media to reinforce self-harm.

Open challenges for future research include fully characterizing the expression and promotion of self-harm activities online, advancing the understanding of correlations between digital activities and offline behaviors, understanding causal mechanisms, and identifying needed attributes for the development of interventions to address digital self-harm behaviors and activities. Key components central to this new research area extend to uncovering correlations and causations between increased online exposure and the physical manifestations of these disorders. Establishing correlations may be particularly helpful in screening Internet usage to identify afflicted individuals or individuals at high risk for self-harm behaviors. Employing data mining techniques within the context of Social Cognitive Theory could facilitate new detection algorithms to identify those at high-risk. Current clinical self-harm screening tools do not reference online activity despite the growing prevalence of digital self-harm content and forums [195].

Multidisciplinary collaborations between clinicians and researchers will be critical in understanding the dynamic relationship between online and offline influences and presentations of the diseases where self-harm is a central characteristic. Some answers will

come from theory. Theoretical constructs such as Social Cognitive Theory can give us a toolkit to understand and articulate the effects of environmental and social pressures on an individual. Other answers will come only through analyzing existing behaviors and practices. For example, recent research demonstrates the potential to identify signs of post-partum depression in social media postings, and, even ways to identify individuals at risk for post-partum depression following childbirth [52]. The analysis of social media postings by adolescents could identify those at risk for self-harm, potentially addressing critical health issues before they exact years of damage on an individual.

Ultimately, a multi-disciplinary approach needed to make sense of digital self-harm, how it manifests and develops, and how it can be addressed through responsive platforms and interventions is a non-trivial undertaking of great importance. As the community begins to answer the outlined questions in this research agenda, we will begin to gain deeper insights into the connections between online spaces and mental health. Because this research will catalyze multi-disciplinary collaboration, the ability to translate these connections into meaningful tools and treatments is a tangible and likely outcome. Defining digital self-harm is an important first step.

In this chapter, I have outlined the various ways in which digital self-harm can be presented. For the remainder of this document, the focus of all digital self-harm activities will be focused within the domain of eating disorders.

CHAPTER 4. IDENTIFYING PRO-ED ACTIVITY ONLINE

I first began my research into the online presentation of eating disorder content through an exploratory study of the Instagram platform [40]. This research focused on identifying how ED-related content is presented online and was a component of a larger, collaborative research project which focused on exploring the impacts of moderation on the lexical patterns associated with ED-related content in over 2.5 million posts between 2011 and 2014. While this research made several contributions to the HCI community, in this chapter I will focus on the aspect that is most critical to my dissertation research – the evolution and transformation of eating disorder related social media tags. This is a critical component of characterizing ED research as it is the identifier used to create the datasets.

4.1 Background

Online Communities and Eating Disorders: As described in Chapter 2, previous research has examined pro-ED online communities on blogs [84], websites [24,226], and related social networks [32]. These studies have used a limited set of search terms to identify the relevant online spaces and then researchers construct qualitative coding schema to analyze the content. These early studies focused on aspects like understanding the content being shared [84], analyzing search patterns [142], and assessing community supports [24,84]. With a few exceptions [32,45], formative work in this area have not examined the communities that have formed on social media platforms like Twitter or Instagram.

Instagram has specific technical affordances that make it an attractive platform for the online ED community. Instagram is a social media platform built upon the sharing of photos and videos. Media provides an influential context for people to learn about body ideals and other distorted imagery of what is seen as beautiful within a given culture

[75,149]. Assessments of youth populations have found that girls under the age of 12 that read magazines reported that pictures influenced their concept of the ideal body shape (69%) and made them want to lose weight (47%) [149]. Approximately 88% of 18-29 year old's use social media, with 71% actively using Instagram [232] compared to the typical age range of eating disorder patients being between 15 and 24 years [226] and the average age for the onset for eating disorders being 18 years [257].

Language Variation: How people communicate online is not straightforward – short-hands, colloquialisms, and regional dialects shape community discourse. This idea of lexical variation can vary based on context. Lexical variation can be defined as the differences in the use of different linguistic constructs and proposed methods to detect how such constructs vary within geographical boundaries [71]. This definition has been further expanded when applied to social media platforms with respect to gender identity [13] and health [224]. Moderation of behaviors that violate the community standards are often sources of lexical variation as the morphing of the language flagged for the moderation filters allows that content to be published within the community.

Understanding shifts in language is an integral aspect to identifying concepts in online spaces: the more variants that are found yields a more complete expanse of the actual activity which provides a more holistic understanding of the concept under investigation.

4.2 Developing a set of search terminology

I used Instagram's official API to collect over eight million public posts in the pro-ED Space between January 2011 and November 2014. First, I obtained post counts for nine seed tags ("ed", "eating disorder", "EDNOS", "ana", "anorexia", "anorexic", "miz", "bulimia", and "bulimic") that are known to be directly related to eating disorder behaviors and activity [45,84]. We collected all posts for each of these tags over a 30-day period which resulted a sample of 434,000 posts with 234,000 unique tags. This sample was used to establish a

baseline to compare against the entire dataset. This sample was used to establish co-occurrence probabilities for all tag pairs. When the tags were sorted, 222 tags were found to have a least a 1% occurrence rate.

The dataset had to be cleaned of mismatched tags/posts that were not related to eating disorders. The selection criteria excluded tags that were broad enough to be used by the general population or be applied to other health conditions. Tags that were excluded included “fat”, “beautiful”, “whale”, “anxiety”, and “depression”. Additionally, tags associated with recovery were also excluded as the focus of this research was the pro-ED or pro-disease community. This meant that tags like “anarecovery” were also excluded. This process was manually done as context was necessary to discriminate the context and make the final decision. This process reduced the dataset from 222 tags to 72 tags. Using these tags to filter the initial dataset, the new dataset contained just over eight million Instagram posts. Finally, to create a dataset that we could confirm were directly related to pro-ED behavior, I removed any posts with three tags (“mia”, “ana”, and “ed”) that did not also contain another tag from the list of 72 refined tags. Additional qualitative reviews found that there were additional mismatches associated with the direct ED tags: “ed” was a common tag referencing popular celebrities (e.g. Ed Sheeran). When these were further filters, the final dataset included approximately 6.5 million posts.

Following the data collection, I devised an approach to identify a set of root tags relevant to the pro-ED community that underwent moderation. First, I constructed a tag usage frequency distribution to identify frequent tags in all crawled posts. For the top 200 tags, two researchers who are Instagram users manually checked for bans or content advisories on these tags. This produced 17 tags that uniquely characterized pro-ED content and have either a ban or content advisory placed by Instagram. Table 4-1 lists these root tags along with the number of lexically variant tags uncovered through the analysis. The ten most popular variants found in the dataset are also reported.

Table 4-1. Root tags, total number of variants in each tag chain, and 10 most frequent lexical variants

Root tag	# of variants	Lexical Variants
ana	9	anaa, anna, anaaa, anaaaa, annaa, annna, annaaa, anaaaaaa, anaaaaaa
anorexia	99	anorexic, anorexie, anoressia, anorexi, anorexia, anorexique, anorexica, anorectic, anorexia, anoretic
anorexianervosa	62	anorexianervousa, anorexianerviosa, anoressianervosa, anorexianevisa, anorexicnervouse, anorexianevisa, anorexicnervosa, anorexinervosa, anorexianervose, anorexianervosia
bonespo	6	bonespoo, bonespoooo, bonespooo, bonesspo, bonesporation, bonessspo
bulimia	49	bulimic, bulima, bulimie, bulimi, bulimia, bulimica, bulimc, bulimiaaa, bulimic, bulimist
eatingdisorder	97	eatingdisorders, eatingdissorder, eatingdisoder, eatingdis, eatingdisorter, eatingdisordered, eatingdisorde, eatingdisorderrr, eatingdisordered, eating_disorder
mia	3	miaa, miaaa, miaaaa
proana	11	proanaa, proanna, proanaaa, proanaaaa, pro_ana , prooana, proaana, pronana, proannaa, proanaaaaaa
proanaorexia	1	proanorexic
probulimia	1	probulimic
promia	4	promiaa, promiaaa, promiaaaa, proomia
secretsociety	55	secret_society123, secretsociety_123, secretsociety123, secret_society, secret_society_123, secretsociety1234, secret_society1234, secret_society124, thesecretsociety, secretsociety124
skinny	18	skinny, skiny, skinny, skinny, skinny, skinnyyy, skini, skynni, skinnyyyy, skinnyyyy
thighap	107	thighgaps, thygap, thighgapp, thigh_gap, thighgap, thyghgap, thighgappp, thegap, thighap, thighgapss

thin	9	thyn, thinn, thynn, thinnn, thynnn, thiin, thiiin, thinnnn, thyyin
thinspiration	101	thynspiration, thinsperation, thinspire, thynsporation, thinsporation, thinspiring, thinspirationnn, thinspirational, thinsparation, thynsperation
thinspo	40	thinspoooo, thynspo, thynspoo, thynspooo, thinspoo, thinspooo, thinspooooo, thynspoooo, thinnsपो, thinspoooooo
Total root tags		17
Total variant tags		672

4.3 Implications

The findings from this research highlights the highly variated nature of how individuals talk about or discuss content related to eating disorders. During the middle of this data collection period, Instagram began heavily moderating eating disorder content within the platform – they began banning the use of certain search terms [14]. Other aspects of this research that are not a component of my personal research found that the pro-ED community has adopted nonstandard lexical variations of moderated tags to circumvent these restrictions [41]. Since the moderation went into effect, increasingly complex lexical variants have emerged over time. Communities that use lexical variants showed an increased participation and support of pro-ED (15-30%) and the tags associated with content on these variants express more toxic, self-harm, and vulnerable content.

Armed with this knowledge, I was motivated to understand the activities and motivations behind engaging in these communities in a deeper, more holistic manner. The quantitative assessments can only illuminate so much, as the computational methods used in this research did not take into consideration any of the media attached to this content or

how the media attached to the content gives a deeper or alternative understanding of the lexical content. This led to a new research study with a more holistic research design with respect to the methods used and the communities that I targeted.

CHAPTER 5. CHARACTERIZING PRO-ED ONLINE ACTIVITY

In this chapter, I describe a set of studies that answers the research question: *What is the presentation and characterization of self-harm activities online?* My research on how ED-related content online is tagged and the types of key terms (and their lexical variants), described in the previous chapter, are a critical foundation for the design of studies that elucidate richer, more in-depth understanding of the actual behaviors that take place within these disease-related tags. Understanding the breadth of activities that take place in these online communities gives platform operators insights into how moderation approaches need to expand/grow or how the platform might best intercede with minimal interventions. Additionally, this knowledge is critical for clinical providers if treatment is more holistic in nature, addressing all components of disease reinforcement and not just those in an individual's offline life. I present two key contributions through this work a platform-independent corpus of terminology commonly used within online ED networks and a set of media archetypes of the online content. The first study makes these contributions for general ED content and the second furthers the inclusiveness of these contributions with the expansion of male-focused ED content. CAUTION: This chapter includes pro-ED related imagery and content that may be a challenge to some readers. Please exercise caution when reading or sharing this content.

5.1 Characterizing the General Online Presentation of Eating Disorders

5.1.1 Background

Marginalized communities and those with lifestyles that are not mainstream, and commonly labeled “alternative,” have often found refuge online [106,155,268]. The social computing community has a long and rich history of examining online spaces that support niche or marginalized communities [62,151,272]. As early as 2001, popular news outlets began reporting on the presence of the alternative communities of anorexic people online [212]. With increasing access to new media platforms, individuals with eating disorders no longer needed to meet up with other individuals with ED through clinics and at hospitals, but instead were able to establish and support thriving pro-disease communities online [23]. Given the preponderance of coordinated, online activity, in this work we attempt to analyze the cooperative and computer-mediated activities taking place within this population. While this online activity is sometimes described as “communities [211],” we take a more conservative stance and characterize collections of user content as “networks” within and across media platforms [109,179].

Online spaces allow people suffering from various issues such as depression [219], sexual abuse [170], and eating disorders [269] the ability to self-disclose aspects of personal identity or behaviors associated with issues while at the same time seeking support for them. For example, participants of suicide-focused Internet forums often situate their participation as not just a “cry for help” but as part of their identity [119]. Online forums allow these identities to be tried out, expressed, and validated [119]. To engender what they hope is seen as an authentic self-presentation, participants often consider audiences when

constructing their narratives about depression and how and when it started [137,138]. The use of these online forums for sharing has also been viewed as a type of identity performance; for example, in the context of self-harm, the self-harmed body becomes a site of intersecting discourses [225].

These presentations often take place in online spaces not specifically dedicated nor designed for such sensitive disclosures. Andalibi et al. looked into depression-related images and captions on Instagram and found that people often disclose personal narratives and stories, negative affect, and self-appearance concerns, and seek social contact [6]. In the context of expressions of loneliness, Kirvan-Swaine et al. found that Twitter expressions of loneliness included temporal bounding of loneliness (enduring vs. transient), the inclusion of context (social, physical, romantic, and/or somatic), and explicit interactivity within the expression (e.g. requesting engagement) [130].

5.1.2 Methods

In this study, I chose to investigate ED activities within the popular social media platforms Twitter, Instagram, and Tumblr. These sites were chosen based on their pervasive use within the 13-24 age demographic [199,232]. To achieve our research objective of characterizing ED support networks online, I first conducted a search across platforms to establish an ED-based dictionary of terms. I then collected posts and established a codebook for both the hashtags associated with the posts as well as a codebook for any embedded media.

Establishing the dictionary: To begin, we researched the terminology associated with general eating disorders and, more specifically, with Anorexia and Bulimia. Based on the

findings from the previous chapter [40] and popular online eating disorder forums, I established an initial set of search terms, T_i (see Table 5-1).

Table 5-1. Initial search terms (T_i) and refined search terms (T_r)

Search Terms	
Initial Search Terms (T_i)	anorexia, proana, pro-ana, bulimia, promia, pro-mia, eating disorder, proED
Refined Search Terms (T_r)	anorexia, proana, bulimia, promia, eating disorder, anamia, proanamia, EDNOS, thinspo, thinspiration, thinspoooo*, thinsperation*
<i>* Due to the filtering used by Instagram, these terms were used in the final search.</i>	

Using the T_i corpus, I conducted an initial search of 50 posts for each term on Twitter, Tumblr, and Instagram – the platforms analyzed for this study – yielding a dataset of 800 posts. Using this set of 800 posts, we identified the most relevant search terms for each site and then compared across platforms. Because each platform has different policies and technical affordances, conducting a one-to-one comparison would not be a truly fair representation of the prevalence of the hashtags within that platform. Several terms were added to the initial corpus based on this analysis (See Table 1) to create our revised search terms, T_r .

Codebooks: I created a small classification codebook for the hashtags (See Table 5-2). I again employed an inductive approach to analyze the 6705 total hashtags collected from the posts in our dataset, of which 1182 were unique. While some of these codes are similar to the media analysis (see below), some are unique.

Table 5-2 Hashtag Analysis Codebook

Anorexia	Food	Other	Suicide/Death
Body	General ED	Post Composition	Weight
Bulimia	Identity	Recovery	
Depression/Sadness	Inspiration	Self-Injury	
Fitness	Mental Health	Social Support	

The codebook for the media analysis also was created using an inductive approach to the analysis of 575 posts within the dataset. A team of three researchers independently open coded a randomized 7% sample (40 posts) of media attached to collected posts. We coded for general themes. Next, we met as a group to discuss themes and further refine the coding taxonomy. The team reached an inter-rater reliability of 86%. The final codebook for this analysis is found in Table 5-3.

Table 5-3. Media Analysis Codebook

Parent Code	Child Code
Body Part	arm(s), back, breast/chest, collarbone(s), face/head, full body, hands, legs, ribs/stomach, thighs
Image Attribute	black and white, color, drawing, food/beverage, individual, group, image_other
Mood	angry, artistic, happy, inspirational, instructional, neutral, painful, provocative, sad/depressed, selfhate, suicidal, supportive
Text	candid, inspiration-disease, inspiration, recovery, no text
Identification	Identifiable, unidentifiable
Focus	Informational, neutral, pro-disease, pro-recovery

5.1.3 Findings

5.1.3.1 Lexical Assessment

I analyze the presence of hashtags used in ED-related social media content and provide a corpus and categorization of these hashtags. A total of 6705 hashtags were attached to the 575 posts in our data set. On average, there were 11.7 tags attached to each post ($SD = 9.0$; range 1-33). Table 5-4 highlights the breakdown of these numbers per platform, since there are differences between each with respect to the technical affordances of each platform.

Table 5-4. Hashtag Analysis

	Total Hashtags	Avg. tag/post	Std. Dev.	Range
Tumblr	3433	20.2	7.9	2-33
Instagram	1939	12.3	8.1	1-30
Twitter	1333	5.42	3.9	1-18

The categories that evolved for this part of the analysis were derived from the hashtags associated with each of the posts in our dataset. Table 5-5 provide a brief definition/contextualization for each category. The full eating disorder corpus organized from this data can be found in Appendix A.

The corpus is divided into direct eating disorder tags and activities or states of being that support eating disorders. Unlike other studies focused on online eating disorder websites [24,28,84,226], we present the full range of lexical variations associated with the posts in our dataset. To our knowledge, this is the largest and most diverse terminology

corpus focused on eating disorder behaviors and activities within the health and social computing domains.

The terms found within the corpus span from traditional terms like “anorexia” and “thinspiration” to more modified terms like “anorectic” and “thynspo”. Table 5-6 highlights examples of these transitions from traditional to modified terms for Anorexia and Thinspiration. We noticed that the same evolutions took place irregardless of the platform where the post originated. These shifts can be related to changes in moderation policies [40], technical affordances [120], and more traditional permutations represented through slang derivations [188]. While understanding the motivations behind these shifts is out of scope for this analysis, highlighting these patterns is an important contribution of characterizing ED-related social media behaviors and points to important future work.

Table 5-5. Hashtag Categories, prevalence, and categorical definitions

<p>Anorexia (15.0%): All terms associated specifically with Anorexia are captured in this category. More specifically, all terms contain some form of “ana” within the term.</p> <p>Bulimia (9.5%): All terms associated specifically with Bulimia are captured in this category. Unlike Anorexia, this category also includes central behaviors and activities crucial to the disease of bulimia like bingeing and purging.</p> <p>General Eating Disorders (ED) (8.9%): Disease-focused eating disorder tags not captured through the Anorexia or Bulimia categories. These ranged from more formal classifications to activities that comprise these specific activities.</p> <p>Body (4.0%): This category encompasses all terms associated with anatomical parts of the human body.</p> <p>Depression/Sadness (4.0%): Emotional terms associated with sadness, depression, or behaviors associated with these sentiments. These sentiments could be reflective of oneself, the community, or the world.</p> <p>Fitness (0.9%): Activity terms focused on the act of physical exertion or identity makers of a fit person/group.</p>
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Food (3.4%): Food and beverage-related terminology as well as diets and terms associated with feelings linked to deprivation of food.

Identity (3.3%): Identity tags ranged from internal perceptions of self, to classifications of being, to characterizations of identity.

Inspiration (7.4%): Terms associated with disease-specific support and other forms of empowerment.

Mental Health (3.3%): Co-occurrences with other mental health illnesses like bipolar and anxiety in addition to general mental health terms and health status.

Recovery/Treatment (5.1%): Classifications of professional and non-professional assistance or help in battling eating related issue.

Self-Injury (7.1%): Self-injury or self-harm terms associated with self-mutilation and tools used for these activities.

Social Support (1.7%): Support for eating disorder behaviors from the support network online. Some might seem counter-intuitive because they focus on using terms like bully and shame to support them when they falter in maintaining characteristics of the disease.

Suicide/Death (5.2%): Explicit and implicit suicidal ideation and the tools used for the acts. Also included feelings associated with death.

Weight (7.6%): Direct individual weights, perceptions of weight, and the process of losing/gaining weight are included in this category.

Table 5-6. Examples of terminology variations

Root	Traditional Terms	Modified Terms
Anorexia Terms	anorexia (34.1%)	ana (27.9%)
	anorexianervosa (1.8%)	proana (11.1%)
	anorexic (1.0%)	anamia (9.0%)
		anatip(s) (3.5%)
		anorectic (1.4%)
		anarexic (1.0%)
Thinspiration Terms	thinspiration (26.3%)	thinspo (44.6%)
		thinspooo (1.6%)
		thinispoooo (13.8%)
		thinspire (0.5%)
		thynspo (3.7%)
		thynspiration (6.4%)

5.1.3.2 Media Analysis

Here I describe the results of the analysis we conducted on the media components of the posts in the dataset. Out of the 575 posts in our dataset, 553 had images - 22 of the Twitter posts in the dataset did not have a piece of media attached to the post. Of the images in dataset, 59.5% of the contained one or more individuals. I coded these images for the types of body parts that were showcased. In total we coded for ten body parts. Overall, the posts averaged 1.70 body parts per image ($SD = 1.22$). Table 5-7 highlights the percentage of images that had a prominent body part, taking into consideration that images could have more than one prominent body part represented.

Table 5-7. Image composition – body parts

Body Part	Prevalence (%)		Body Part	Prevalence (%)
Arm(s)	10.2%		Hands	4.2%
Back	5.1%		Head/Face	20.3%
Breast	18.6%		Legs	15.3%
Collarbone(s)	10.2%		Ribs/Stomach	39.8%
Full body	13.6%		Thigh(s)	22.0%

I analyzed images with one or more individuals for gender presentation and identifiability. These were coded as feminine (61.0%), masculine (5.9%), or unknown/other (33.1%). Figure 5-1 shows a representation of each of these categories. Regarding identifiability, 79.6% were unidentifiable, meaning there were not enough characteristics in-focus or present to give the coders a sense of the likeness of the individual.



Figure 5-1. Media examples of gender: masculine, feminine, and unknown/other

Just over half, 54.1%, of images had text associated with the image. When I analyzed the text to better understand its purpose in association with the image, I identified three categories associated with the sentiments shared. Text that embodied sentiments supporting illness was found in 21.2% of the total dataset. For example, “Do not reward yourself with food...you’re not a dog” and “I wish my bones showed like this” exemplify sentiments shared that support behaviors associated with eating disorders. Text that

embodied sentiments supporting recovery was found in 6.1% of the total dataset. “I ate so well today; I am so proud!” and “Repost to save a life – eating disorder hotline: 1-800-931-2237” represent text shared demonstrating recovery or support to transition into recovery. The third and last category of text embedded in images was candid statements. Examples from this category include “Easily forgotten because I don’t matter” and “I hate the feeling when you randomly feel depressed...there’s no warning, no apparent reason. It just happens.”

5.1.3.3 Media Archetypes

The analysis of the media posted on these social platforms also identified certain archetypes related to ED posts. While all media did not fall into one of these foci, the following are representative of a majority of posts within the dataset

Thinspiration: Posts in this category offer inspiration to both themselves (individual) as well as others within the network (others). Thinspiration or “thinspo” are media that encourage individuals to be as thin as possible. Figure 5-2 is an example of thinspiration rated to activities or negative reinforcement.

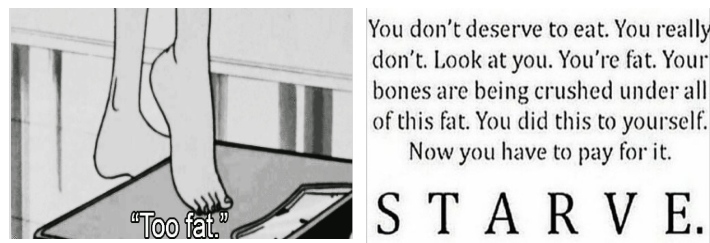


Figure 5-2. Media Archetype: Thinspiration images - activities

Another category of thinspiration is images of individuals and body parts to encourage individuals to strive for the “ideal” body type. This category includes “bonespiration” or “bonespo”, characterized by the ability to see as many of your bones through your skin as possible. Figure 5-3 is an example of these types of media.



Figure 5-3. Media Archetype: Thinspiration - Body

The ED Journey: Before-and-after compilations are a way for individuals to share progress and are likely used by the creator as motivation to “keep going” in their pursuit of the ideal body type. Media in this category focus on the journey associated with weight loss. Figure 5-4 highlights the typical composition of these images – a before and after shot with some type of time annotation to denote duration of the journey. Artistic depictions also highlight this journey as well as the corresponding emotions associated with reaching these different benchmarks (see Figure 5-5).



Figure 5-4. Media Archetype: The ED Journey – Before and After

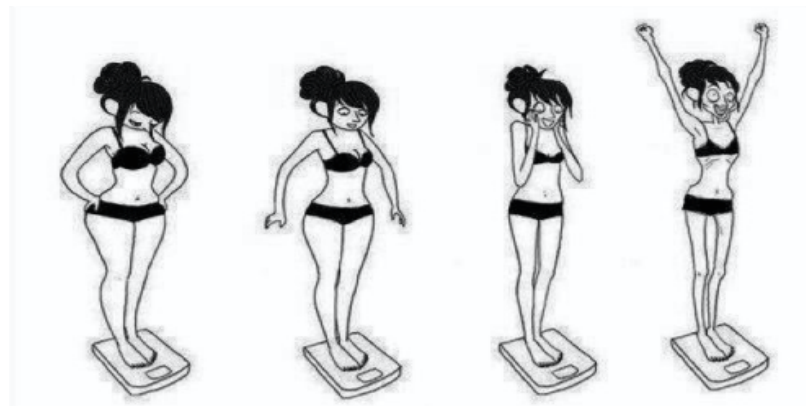


Figure 5-5. Media Archetype: The ED Journey - Artistic

Diet: Foods and drinks are a central tenet for eating disorders in practice and in diagnosis.

They are also used to evoke sentiments of social support and the sharing of best practices.

Figure 5-6 highlights the types of images in the dataset shared as part of a “balanced meal” or support to avoid consuming calories.



Figure 5-6 Media Archetype: Diet

Mismatches: For images within the mismatches archetype, the image and the associated hashtags are the antithesis of each other. This strategy could be implemented by the user to circumvent the censorship technologies employed by the social media platforms; it could be a strategy to impact large swathes of “wannabes” or those on the periphery of the network; or it could be an attempt to communicate actions and behaviors to the network without using media that could potentially trigger or deeply affect other individuals.

If analysis only took place using the post text, void of the tags or images, some posts would show no indication of being a potential trigger. Figure 5-7 was taken from Twitter. The associated post stated “Thank you for 100 followers. Lovely people!” The associated hashtags are “thinspo,” “ily,” “skinny,” “anamia,” and “ed.” There is clearly a mismatch between the tone of the post text and the hashtags associated with the post. While the hashtags and the media are synergistic, there is a definite mismatch with the attached post text.



Figure 5-7 Media Archetype: Mismatch Example 1

Another example is taken from Instagram (Image 9). Again, there is a mismatch between the focus of the post text and the focus of the image and associated hashtags. The text of the post stated “Erg! I gotta pee again! (U didn’t need 2 know that, didyou?)”. This is less connected than the previous example. The hashtags associated with this post include “ana,” “anorexia,” “anorexic,” “skinny,” “thin,” “anamia,” “mia,” and “bulimia.” The post includes the text “Do not give up what you want the most for what you want at the moment.” Again, the hashtag and media are synergistic, yet the post text is an almost redirect from the content.



Figure 5-8. Media Archetype: Mismatch Example 2

Suicidal expression: Media representing suicidal ideation or expressions associated with death were present across all platforms. These images used varied types of presentation; use of quotes or written text was a particularly popular presentation style. Another popular form of media associated with suicidal ideation or death is portrayal of the act of a death or showcase of a tool that one would use to cause death. Figure 5-9 provides an example of each of these types of suicide-related imagery.

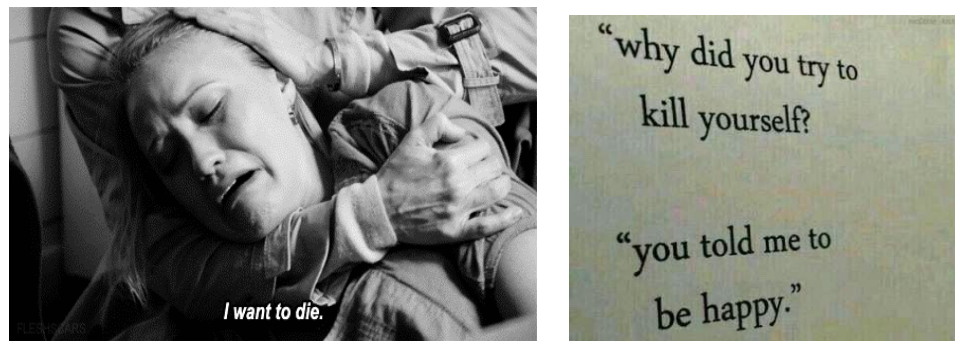


Figure 5-9. Media Archetype: Suicidal Expression

Self-harm: Media representing self-injury behaviors such as cutting and bruising were also found in our dataset. These images (Image 12) were connected to sentiments of depression and self-hate.



Figure 5-10. Media Archetype: Self-harm

5.1.4 Implications

The consequences of injecting technology into a mental health issue like eating disorders creates new nuance to the lived experience of the person with the disease because the size of the audience increases, the ability to detach from the activity decreases, and the artifacts from the activities persist online for those involved and others to re-digest at any given time. It is interesting to compare the trajectory of digital self-harm, with respect to eating disorders, to that of cyberbullying. Initial research into these changes in the context of cyberbullying showed that technology-mediated activities potentially have more dire consequences than traditional presentations of those same activities [35].

Multiple strategies have been put in place to address cyberbullying: the development of anti-cyberbullying intervention prevention programs, mandatory reporting laws, and government-mandated protocols [113]. Other strategies have included creating public-private partnerships between the government and mobile phone providers like that seen with Vodafone and the NetSafe program in New Zealand. In this partnership, if an individual is found to be a repeat cyberbully, they can have their service temporarily interrupted or even have their accounts deactivated [278].

While some of these interventions might not be applicable when appropriated for addressing digital self-harm, they represent an integral step - multiple stakeholders coming together to develop strategies for addressing the issues ED posters are at risk for harm to themselves while they are encouraging harm to members of their network. What is likely is that the pervasive access to online content is amplifying their reach and perhaps their offline, harmful behavior.

Much as technology has changed what it means to be bullied, I show in this work some of the ways that technologies, and the communities that form on technological platforms, mediate and potentially have changed what it means to have an eating disorder. We can learn from the evolution of bullying into cyberbullying and apply similar coping strategies to the online behaviors that support eating disorders.

5.1.5 Challenges for Social Computing Research

The process of how social computing researchers make sense of the data shared via the internet has limitations. We as researchers can speculate as to motivations and drivers, but the methods limit the understanding of the deeper cultural contexts. If we were to use a mixed methods approach and were able to interview individuals immersed in these communities, we could potentially have uncovered evidence as to why this phenomenon is taking place. Without this contextual validation, we are limited to our ability to speculate and conjecture correlations and causations related to what is driving these behaviors and the connections of these online activities to an individual's actual lived experience.

The use of only qualitative analysis would have resulted in a different understanding of what was taking place within this dataset. On its own, analysis of hashtags was sometimes insufficient or misleading in relation to the tone and sentiment of an entire post. Terms within the Social Support, Inspiration, Identity, and Food/Eating categories in particular were not well-aligned with whether they supported disease, recovery, or neutral. Terms are shared between these communities with increasing frequency, and therefore many have become increasingly general in nature.

“I’m fine” or “bodypositive” are terms that we saw represented in both pro-disease and pro-recovery posts. Without the context of the associated media or post content one could deduce or categorize these as pro-recovery terms. In actuality, the terms are used both to justify the normalcy of the diseased behavior as well as signal representation of the recovery process. Additionally, hashtag or individual post analysis often does not consider responses from others (such as comments or retweets) and the social ecosystem that evolves around social media content. A post’s social surroundings may uncover meaning that would be missed by looking at the post in isolation.

This observation calls into question what we can really learn from analyzing certain elements of online posts in isolation, not only in the context of ED populations, but in online media research more broadly. If we think of an individual post as a small ecosystem, then the sum of the individual parts of that post is greater than those individual elements. By only analyzing some parts, we are potentially incorrectly analyzing the intentions or actual presentations of the artifacts, and thus potentially misrepresenting marginalized online communities.

Another key challenge is that of moderation. In the early days of the Internet, eating disorder networks typically organized around bulletin boards, chat rooms, and specific websites [28,226]. These were public facing platforms that were characterized by group activities and organization. Therefore, it was much easier for these networks to be discovered and for their activities to be halted, which typically happened when the ISP shut down access to the webpage or the platforms; Yahoo!, for instance, could shut down certain chat rooms [226].

Social media platforms have moved the scope of network construction from the group to the individual. Instead of a formal chat room or bulletin board, ED network members use their personal social media feeds to connect with the, now distributed, ED support network(s). The uniting threads within a singular platform or across multiple platforms are hashtags. By moving to this organizational structure, these networks are able to “hide in plain sight” on popular social media platforms like those analyzed in this study. This fluid, individualized presentation, can make researching these populations, and potentially deploying interventions, difficult.

5.2 Accounting for Biases in the Original Research Design

The previous section outlined a body of work that characterized digital self-harm activities across various social media platforms [195]. Upon reflecting on this work, I found a key missing demographic: examples of male-related eating disordered content. Many stereotypes surround EDs, namely that they are believed to be limited to women striving to meet Western ideals of a slender ideal body type [98] or that they are diseases commonly found in wealthy, higher socio-economic classes [280]. Gender stereotypes posit that men have lower risk levels of EDs due to lower levels of cultural pressure [273]. While these stereotypes might still be in popular fashion, research has debunked these theories, showing that individuals of different class structures [206] and genders [173] are just as likely to show indicators of ED behaviors and patterns.

Understanding this context, I conducted a replication study to the previous section that would allow me to explore male-related expressions of eating disorders using various gender expressions to define ‘male’ and ‘masculine’ [193]. Because I reviewed public data,

I was therefore unable to inquire about one's gender identity directly therefore I am only able to assess the external appearance of gender identity as expressed through the social media content [122]. I used the formal definitions of male ("an adult human male"²) and masculine ("having qualities or appearance traditionally associated with men, especially strength and aggressiveness"³) to situate our understanding of male gender expressions within the dataset. By replicating the methods of the original study, yet expanding the terminology used to build the dataset, this allowed me to validate and extend the media archetypes in addition to expanding the corpus of ED terminology. The result is a more inclusive, holistic understanding of digital self-harm activities related to eating disorders.

5.2.1 Background

A critical component to this research is the concept of gender and how it is characterized. Historically, male presentations of EDs have been perceived as rare and atypical — a perception that has resulted in the systematic underrepresentation of males in ED research [177]. Since my own previous work shares this bias [195], in this study I was eager to gain a more gender-diverse understanding of ED presentations online. To do so, we drew from gender socialization theories that engage gender as a social role distinct from biological sex. These theories view gender as at once a spectrum (as posed elegantly in the relational theory of men's health, which views the presentation of gender through the lens of different cultural and societal constructs [58]) and quantized (as shown by the Sex Role Theory of socialization which focuses on "two fixed, static, and mutually exclusive roles" [128]).

² Man. 2018. The Oxford Dictionary. Cambridge University Press

³ Masculinity. 2018. The Oxford Dictionary. Cambridge University Press.

In this work I also take care not to view gender in isolation, but as a social role that interacts with other facets of an individual's identity. A useful theory here is Intersectionality, a framework that takes into consideration how gender connects with other aspects of social stratification like race [59] or sexual orientation [254] and is used to identify how interlocking systems of power impact marginalized individuals [57]. The pressure to conform to a specific gender role, especially within the highly gendered space of ED, can be considered a form of oppression, and many male-presenting individuals with EDs encounter intersectional challenges. For example, gay and bisexual men have a higher prevalence of EDs than heterosexual men [80] and are seven times more likely to admit to bingeing and purging than their non-gay peers [11]. Other HCI researchers have begun to examine the complexities of intersectionality and compounded marginalization across a variety of domains such as ICTD [66,116], management information systems [242,245], and design [111,270]. Furthermore, it is increasingly understood that gender is an essential element to an accurate understanding of health and illness [9].

Male or masculine examples of EDs are not new as there are records going back to the late 1600s documenting a case of a 16-year-old male with food restricting behaviors [168]. Unfortunately, EDs are commonly assumed to be a female issue. This bias means that males with EDs are often overlooked, understudied, and under-reported [101]. Within the Anorexia Nervosa domain, males account for less than 1% of the populations researched [174]. These levels of representation conflict with the reality that males represent a larger percentage of individuals struggling with EDs than what was previously believed. The NIH estimates that males represent 5% to 15% of patients with anorexia nervosa and 35% of patients with binge-eating disorder [281]. When non-ED settings are assessed, these rates

can rise drastically as seen with males making up to 67% of avoidant/restrictive food intake disorder diagnoses [181]. Within the minority of studies focusing on men, a majority of the focus has been on the psychopathology [157], treatment outcomes [216], symptoms [262], and experiences while receiving services [216]. The clinical constructs that define EDs also show gender bias towards females. The current diagnostic framework for EDs, as it relates to males and masculine representations, has recently been called into question [33,174–176]. While there have been positive movement to address this issue, most notably the removal of amenorrhea from the DSM criteria Anorexia Nervosa, there is still a lack of patterns attributed towards aspects of orthorexia or reverse anorexia that are more typical with male presentations. These tensions within the diagnostic criteria of EDs and male representations point to a possible inadvertent gender bias in data that has used clinical constructs as a framework and filter for online analysis. These studies highlight the growing need for a more inclusive approach to ED study design and research.

Inspired by these concepts, in this research I sought not to define or assign a gender to any particular person, but to (to the best of our ability) understand the interaction between their gendered presentations and other online behaviors. This approach allows us to draw attention to differences within and similarities across gendered representations of ED content in online spaces. This research contributes to a growing body of HCI research in both gender and mental health domains.

5.2.2 Methods

To build the dataset, I started off with the only male-related ED from our previous study's dataset (menwithED) as the initial search term. Using menwithED, I conducted an initial

search of all posts from Instagram, Twitter, and Tumblr from January 1, 2018 to July 31, 2018. After removing the posts related to erectile dysfunction, I ranked the most popular tags across the platforms and thus identified the most relevant male-related search terms connected to the previous study's search terms. 'MenwithED' was a very limited search term yet resulted with additional terms 'menwithanorexia' and 'manorexia'. Expanding the search with these terms resulted in the addition of 'manorexic' and 'malethinspo'. Additionally, based on the literature we include the term 'bigorexia' in the final dataset [2,95,160,164,169,202]. The final search terms used for this study included: manorexia, manorexic, malethinspo, and bigorexia.

Using the refined search terms, I collected data from January 1, 2018 to August 15, 2018 from Instagram, Tumblr, and Twitter. To comply with platform policies and community standards, the data for this study was collected manually using the platforms' in-platform search tools. As with the previous study, I collected only English language public posts. The dataset included a total of 664 posts: 480 from Instagram, 104 from Tumblr, and 71 from Twitter. We randomly sampled 50% of this dataset, ensuring that platforms and search terms were accurately represented within the final dataset. We qualitatively analyzed 332 posts.

For the media analysis, the initial codebook took a deductive approach in that I started with the codebook from the previous study [195]. To build upon it, I took an iterative, inductive approach: I used the initial codebook to categorize the hashtags and posts within the dataset. If a category did not exist, I flagged the post. Three researchers met several times as a group to discuss these posts and the new concepts found within the data, finally refining them into an additional four new categories. Initial categories include anorexia, body, bulimia, depression, fitness, food, general, ED, identity, inspiration, mental health, other, post composition, recovery, self-injury, social support, suicide, weight. New categories include bigorexia, drugs, gender, sexual orientation, social elicitation. I used

these categories to organize and compare the terminology corpus and media analysis. The team and applied this codebook it to a randomized 10% of the new dataset (33 posts). The team discussed the content and agreed upon an updated expansion to the code book. The team then co-coded an additional 20 posts to ensure we obtained consensus. The codebook is outlined in Table 5-8. All bold codes are new additions to the codebook.

Table 5-8. Men with ED Online Modified Codebook

Parent Codes	Child Codes (new 2019 codes in bold)
Body Part	arm(s), back, breast/chest, collarbone(s), face/head, full body, hands, hip(s), leg(s), ribs/stomach, thighs, waist, buttocks, feet, neck, shoulder
Image Attribute	black and white, color, drawing, food/beverage, image (individual), image (group), image (other), selfie video
Mood	angry, artistic, happy, inspirational, neutral, painful, provocative, sad/ depressed, anxious, promotional, secretive, strength
Text	candid, inspiration (pro-disease), inspiration (pro-recovery), no text, not disease related, not pro-disease
Identification	identifiable, unidentifiable, not me
Focus	informational, neutral, pro-disease, pro-recovery, deception, informal, showcase/display
Sexual Orientation	bisexual, heterosexual (context), heterosexual (denoted), homosexual (context), homosexual (context), not given, pansexual
Gender	androgynous, female, gender fluid, male, not given, transgender

When assigning codes to the hashtags and the social media posts, I took a straightforward approach. First, the only category where the researchers made inferences on the content was the Mood category. During the iterative process, the researchers discussed type of mood that the hashtags and posts exuded and thus is a subjective assessment. For the Sexual Orientation/LGBTQ and Gender categories, no inferences were

made. These categories included child codes of ‘not given’ to indicate if no specific text or media content indicated a specific gender or sexual orientation. It should also be noted that we are not inferring that the individual posting is representing a specific gender or sexual orientation, only that their specific post had representations of these categories. Some of the hashtags in our dataset represent multiple categories. These include tags like ‘edtransboy,’ ‘transrex,’ ‘compulsive exercise,’ and ‘gayanorexia’. For this reason, we attached multiple codes to each term to reflect the various categories that these more complex terms represent

5.2.3 Findings

5.2.3.1 Lexical Assessment

I analyzed the presence of hashtags used in masculine ED-related social media content and provide a categorized corpus of the terms. A total of 8762 hashtags were attached to the 664 total posts in the full dataset - 2570 of which were unique. On average there were 13.2 tags per post (SD = 8.9; range 1-30). This is comparable to the 2016 study which had an average of 11.7 tags per post with a SD = 9.0 and a range of 2 to 33. Table 5-9 shows the breakdown of these statistics by individual platform.

Table 5-9. Men with ED Online Hashtag Analysis

Platform	Total # tags	Avg. tag/post	Std. dev.	Range
Instagram	7598	15.54	8.65	1-30
Tumblr	923	9.05	6.38	1-29
Twitter	241	3.39	2.15	1-10

Validating the need for expanded search terms. I was interested to know how many of the posts in our dataset would have been found using only search terms from the 2016 study. Using only the final search terms from the 2016 study to filter our current dataset, 36.7% of the current dataset would have been collected. When we expanded this to include the entire ED terminology corpus, only 76.1% of the dataset was accounted for. This means that without the expansion of the terminology found in this study, 23.9% of the dataset would be missing from the knowledgebase generated from this expansion to the previous research. We compared the hashtags against the corpus from the previous and removed all duplicates. General ED, body parts, and fitness categories all contained greater number of terms than the 2016 study. Table 5-10 highlights the breakdown of discoverable content per social media platform.

Table 5-10. Comparison of Hashtags between [195] and [193].

	Instagram	Twitter	Tumblr
% of posts discoverable using 2016 search terms	29.8%	14.1%	85.3%
% of posts discoverable using 2016 corpus	77.1%	45.1%	93.1%
% of posts that would not have been collected using results from 2016 study	22.9%	44.9%	6.9%

Categorical Assessment. While there is similarity between the previous study and our current study with respect to the hashtag metrics, the distribution across the organizing categories are drastically different. Table 4 shows these stark differences. The anorexia and bulimia category saw the greatest decreases when comparing the results of this study with the 2016 study's findings; 10.1% and 7.4% respectively. The male-focused dataset also saw less prevalence of self-injury and suicidal hashtags. To contrast these findings, identity

and fitness tags saw the greatest increase compared to the previous results. Identity terms were highly varied. The included terms associated with how an individual might characterize themselves ('grunge,' 'handsome,' 'body-builder,' 'model,' 'blogger,' and 'self-made') or related to their religion ('Christian,' 'Muslim'). Behavioral identity aspects were also identified in the dataset ('shameless,' 'shallow,' and 'superficial'). Other terms were associated with specific aspects of identity like 'body-image' and 'appearance'. Fitness tags focused mainly on 'bodybuilding,' 'workouts,' 'bulking,' 'gym,' and 'exercise.'

Lexical Variations. Like previous studies [40,195], we also saw lexical variations across the different platforms and different hashtags. Examples include 'anorexya' and 'anoreskya' for the root-term 'Anorexia' and 'big0rexia' and 'bigorexique' for the root-term 'Bigorexia'. While the patterns of variation are similar to the previous research in this domain, we found less lexical variations than these studies.

Gender Descriptors. In the previous study, there was scant representation of gender in the dataset. By purposefully utilizing a lens of male gender and masculinity, our approach insured that the current dataset has a larger corpus of male gender-related terms. 4.9% of all hashtags were directly related to a gender marker. It should be stated that we are not inferring the gender of the individual posting the content or the subject of the content, we are merely assigning a category to the hashtags attached to the post. The gendered terms in our dataset were not just male focused — of the 4.9%, 86.5% were explicitly male oriented and 11.9% were explicitly female oriented. Since one of the major search terms bigorexia is gender neutral, we anticipated seeing some slight variance in the gendered markers associated with the content yet were surprised by high prevalence of explicit female/feminine tags.

LGBTQ/Sexuality Descriptors. Sexual orientation was another category of tags that was not present in the 2016 study. This category accounted for 1.9% of all tags. The hashtags in our dataset ranged across a spectrum of LGBTQ tags from gay to queer to bisexual to trans. Also included were slang terms used in the LGBTQ communities like ‘twink,’ ‘musclebear,’ and ‘instagay.’ Examples of posts are further explored in the Media Analysis. As previously stated with gender-specific hashtags, no inference was made to the sexual identities of the poster or the subject of the post, just the assignment of a category to hashtags attached to the post.

5.2.3.2 Media Analysis

Of the 332 posts in our dataset, 69.4% had media attached to the post. Based on the technical affordances, 100% of the Instagram posts had media attached to the post. 56.9% of posts on Twitter and 33% of posts on Tumblr had only text associated with the post. The color of images is one of these, with having 37% less black and white images than the previous study. We also found less images within the other category, which includes images of places and things. Additionally, there was a drastic decrease in the number of images directly focused on specific foods and beverages (9.2%). The rest of the image attributes showed little variance between the previous and current studies. In our dataset, 74.0% of the images contain one or more individuals, an increase from the previous study’s 59.5%. We coded these images for the body parts that were the most prevalent in the image. The original codebook had ten body parts, to which we added an additional four. These posts averaged 2.5 of unique body parts per image ($SD = 1.66$) with 27.3% featuring the entire body. Table 8 shows the breakdown and how the code class compares to our previous data. There are stark differences between the body parts that are highlighted in general and masculine ED posts. In this study, the masculine posts tend to showcase the arms, breast/chest, and shoulders where the previous study found posts focused mainly on the face/head, ribs/stomach, and thighs.

5.2.3.3 Media Archetypes

The analysis of the dataset validated the archetypes found in the previous study while identifying new archetypes. The archetypes described below are not comprehensive, but are representative of a majority of the posts within the dataset.

Thinspiration (Malespiration). Similar to the previous study, we found examples of text and media supporting thinspiration. In the diary-style documentation of an individual's ED, they shared, "Today is a great day! I am 723 calories today and have been exercising since 10 am. I really happy since I haven't logged that." While this post could be viewed as an important aspect of the individual using the social media platform to document or keep a diary of their progress, this also serves as a form of social support and 'thin inspiration'. Within the thinspiration category there were also similar patterns of sharing images focused on specific body parts viewed as desirable or ideal. Figure 5-11 highlights these ideals, from the both the bigorexia and anorexia perspectives.



Figure 5-11. Media Archetypes – Malethinspo

ED Journey. The journey of typical EDs is a current status check of weight loss. Examples of this archetype within the male genre are represented within the dataset. Unlike the previous study, ED journey posts and media typically do not string together momentary

updates on weight status as they typically have a starting image and an image of the individual in the moment and are void of metadata like weight, girth, and height. For the bigorexia genre, documenting the journey is the inverse of weight loss where additional muscle is the desired ideal. Additionally, there were several examples in the dataset of connecting the bigorexia and gender transition journeys. Figure 5-12 represents a birgorexia journey and a trans male to female transition and bigorexia post.



Figure 5-12. Media Archetypes – ED Journey

Diet & Food. Food and beverage play a central and fundamental role in any given ED. Unlike the previous study, the diet and food tags did not display examples of fruits, vegetables, or portioned meals. We observed a focus on protein and protein supplements used for building muscle mass as well as diet drinks and cigarettes as means to suppress the urge to eat.

Missing Media Archetypes. The dataset for this study contains few examples of the self-harm and suicidal ideation that were more prevalent in the previous study. The infrequency of these posts in our dataset means it is not representative to include it in the discussion of media archetypes for male ED. An example of text associated with the one self-harm post

included ‘cutboys’ attached to an image of a razor blade. Examples of text associated with the suicidal ideation posts include ‘male suicide,’ ‘suicide,’ and ‘suicidal’. The media attached to these posts were mainly black and white images or images of thinspiration. Additionally, there are no representations of the mismatch that the previous study found represented in their data. This archetype was defined in the previous study as a post where the author uses media and text that share no relationship to one another. An example of this would be a post where the post text describes excitement about a football game, but the attached media is of thinspiration and the hashtags support pro-ED behaviors. Therefore, there will not be a discussion of these media archetypes in this paper.

5.2.3.4 New Media Archetypes

Sexuality Representation/LGBTQ. In the previous study, one term in the ED terminology corpus was related to any expression of sexual preference: homosexual. The current study contained 48 unique LGBTQ-related terms that spans five categories within our dataset. Examples of these terms include: gayarab, gaybooty, gaylord, gaymuscle, homo, instagay latinotwink, lgbt, musclebear, queer, trans, transrexic, and twink. The dataset does not contain any female-focused expressions of sexuality; given the focus of the paper this observation was not surprising. However, gay, bisexual, and queer terminology were all present in the dataset. There were several different general types of LGBTQ posts in our dataset. The first type was where the individual would leave no other context of sexuality except for one or two hashtags. In these posts, the media attached have limited to no indicators of sexual identity of any kind. Examples of hashtags that were attached to these types of posts include ‘gaymuscle,’ ‘gaytwink,’ and ‘queen’. Other posts used LGBTQ

imagery, like the pride flag, in addition to related terminology. Figure 5-13 depicts several examples of media that connected ED content with sexuality.



Figure 5-13. Media Archetypes: Sexuality Representation/LGBTQ

Female Representation. Bigorexia tends to be discussed mainly within male or masculine contexts. In our dataset, we found exemplars of women displaying the same patterns of their ED journey and inspiration pictures that showcase specific body parts. We also found media consistent with the archetypes found in the 2016 study, including thinspiration focused on thigh gaps and artistic expressions of sadness and depression. We also found female content using the ‘bigorexia’ tag. This content departs from the traditional feminine examples of the before and after media that focuses on becoming thinner and is similar to the masculine bigorexia media that focuses on the development of muscle definition and tone.

Social Capital Elicitation. While analyzing the Instagram data, we found a group of posts that were broadcasting both ED content and behaviors while eliciting the development of social ties through the use of ‘like for a like’ or ‘follow for a follow’. Other examples include: ‘follow4follow,’ ‘follow4followback,’ ‘like4like(s),’ ‘like4follow(s)’ and ‘followforfollowback’. There was no context given in any of these posts as to why this

convention was used and there were no commonalities across the posts in this category. Other themes and behaviors were distributed across the other categories without any perceived patterns.

Direct Denial of ED Behaviors. During our analysis of the dataset, we found an interesting characteristic within the Tumblr and Instagram data: the use of ‘Not me’ in the text of a post that is related to EDs. Figure 5-14 highlights the tension between this tag and the surrounding images and text in the post. This pattern was not reported in the previous study nor was it present in any of the female-related posts in this study’s dataset. The ‘not me’ phrase was used in 19% of the posts in our dataset.



Figure 5-14. Media Archetypes: Direct Denial

5.2.4 Implications

The findings demonstrate that while there are similarities in the online presentation, there are stark differences between the previous and current study indicating that gender roles connected to ED content, while providing some similar results, resulted in new knowledge generation.

There are tensions in the literature related to gender and the characterization of EDs. Existing clinical ED frameworks are biased, as they are built upon a body of research that

over samples female patients [161,173]. Most definitely, social stigmas play a role in this sexual dimorphism. Additionally, males are less likely to seek help from a mental health professional in part due to these social stigma [106]. Due to this complex foundation, it would be expected that the online expressions related to this domain are equally, if not more, complex in their composition. In my previous research, there was a fundamental assumption that the search terminology used, which is based on clinical symptomology and terminology, was inclusive of all struggling with EDs – an explicitly stated rationale for utilizing clinical terminology was to help bridge the divide between HCI and traditional health research in the technology and ED domain [195,200]. This research illuminates the gender bias within the health discourse of EDs is also present in previous ED-focused HCI research [39,85,195,200,260].

The research on cross-sectional data suggests that males with ED have distinct differences from females with ED. One of the key differences presented by Striegel-More et al. is that males are more likely to report a greater array of psychiatric comorbidities [237]. Compared to our previous study, our current male-focused study had an increase of 1.9% in declarations of comorbid mental health issues with an additional nine new terms, most of which focused on ADHD, OCD, and obsessive tendencies. When assessing differences in characteristics of specific EDs, we find that the data from this study further validates past research findings that offline behaviors are consistent with online presentations. Within the anorexia community, men tend to focus on different dietary goals, those that enhance leanness and muscularity over thinness and emaciation [208]. Our data confirms this finding through the content within the identity, fitness, and diet categories of our content analysis. When we compared the terms associated with the presentation of weight, the 2016 study (utilizing more feminine based root terminology) found terms associated

with thinness like ‘thyn,’ ‘size0,’ and ‘beskinny’ compared to the current study (utilizing more masculine root terminology) which found terms more associated with muscularity like ‘thick,’ ‘jacked,’ and ‘gains.’ With respect to bulimia, males have been found to be less likely to engage in activities like purging and the abuse of laxatives and are much more likely to practice extreme dietary restriction and excessive exercise [237]. Our data supports these observations with an 8.1% change from the previous study with respect to different fitness activities found within the social media posts. Additionally, the previous study reported mentions of diuretics and different weight loss aides like laxatives. In our current study, the term diuretic and laxative do not appear in the dataset, yet drugs like anabolic steroids and hgh are 3x more prevalent than disclosures of self-injury or suicidality

5.2.5 Exacerbating Existing Healthcare Disparities

HCI researchers are building upon our shared knowledge of how different types of mental illness are characterized online in an effort to detect if someone is at risk for exhibiting symptoms or characteristics of a given mental illness [46,48,50,51,135,187,201]. These are critical first steps in an ultimate goal of creating tools that potentially intervene at the early stages of self-presentation or initial searching for the type of content outlined in this paper and in the work of those trying to predict mental illness. Therefore, it is critical that the foundational knowledge used to build tools that strive to detect mental illness is as holistic and inclusive as possible.

If this knowledge base is limited in its capacity to identify individuals of different genders, cultures, or other type of segmentation of the general population, the technology

runs the risk of further exacerbating existing healthcare disparities. In the previous section, we reviewed that males have additional social stigmas and both structural and cultural barriers to care with regards to traditional avenue of treatment for an ED. If the assumptions underlying technological advances in early detection and screening do not address these deficits, then the technology is primed to further compound healthcare disparities related to gender and culture.

5.3 Summary

Eating disorders are not a new phenomenon and will continue to persist within the interconnected design of current popular social interactions. As social computing researchers, we will play an increasingly important role in understanding how the platforms and technologies that we create are used and misappropriated for negative health purposes. In this chapter, I have analyzed the online, socially constructed presentations of eating disorders across several social media platforms, distilling common and defining the various media archetypes. In this process, I have also created a corpus of terminology and lexical variants associated with eating disordered terminology. Through internal reflection of these results, I found my initial work to be biased against non-feminine or atypical representations of eating disorders. This lack of a more inclusive and multidimensional understanding of the presentation of ED content online stems from, and further exacerbates, the marginalization of males in health-focused ED research. While it has been important to use clinical terminology and contexts in the grounding of HCI research focused in this domain, it is equally as important to recognize the limitations. These limitations include the potential disparities associated with frameworks biased to female-centric symptomology and psychopathology. As the HCI field continues to develop

methods and technologies for the detection and treatment digital self-harm, we must take into consideration examples of bias that was outlined in this chapter. If not, the community risks further exacerbating embedded healthcare disparities that we might not know even existed in the first place.

CHAPTER 6. CLINICAL UNDERSTANDING OF ONLINE PRO- ED ACTIVITY

In this Chapter I explore the process of connecting the knowledge base developed in the previous chapters to a clinical population. I first describe the partnership with the healthcare system that made this research possible. The collaboration with the health system allowed for a deeper understanding of the dynamic network of care available to patients who have an eating disorder in addition to the multitude of entry points patients have in an effort to access care. This relationship had several constraints and facilitators for this research and meaningfully impacted the design of this research. I then present results from an interview study with various types of healthcare providers, shedding light on how patients discuss technology within the clinical setting and how providers respond.

6.1 Healthcare Partnership

The research in this chapter would not be possible without the partnership with Parkview Health. Parkview Health is a not-for profit, community-based health system serving northeast Indiana and northwest Ohio. The network is comprised of nine hospitals, an inpatient behavioral health center, two specialty institutes (heart and cancer), and a research center. I expand on this partnership, integral to the design and execution of the research, in the subsequent sections. Figure 6-1 highlights the various partners and how they interact engage with patient care.

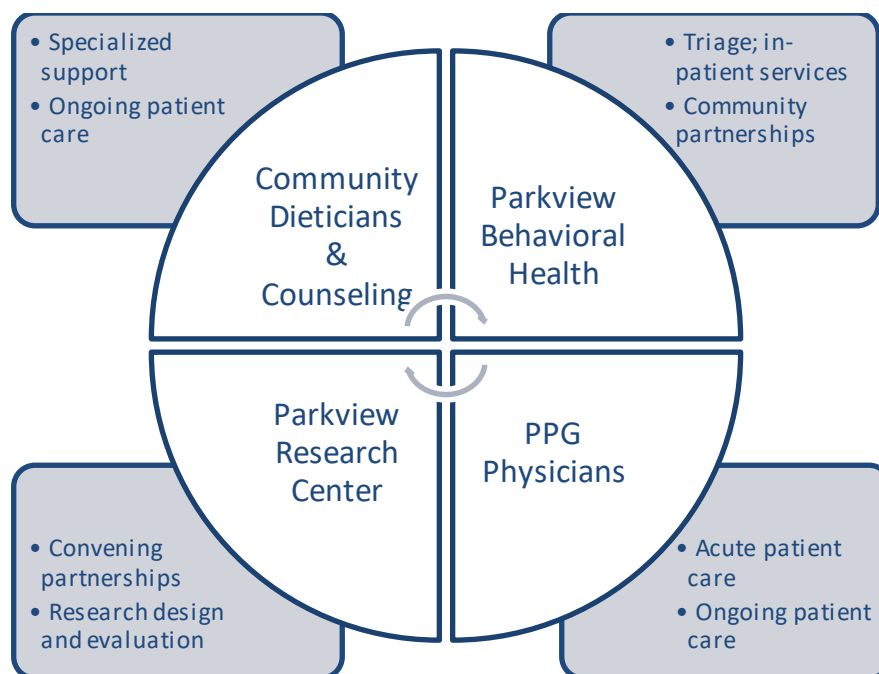


Figure 6-1. Healthcare providers for patients with eating disorders in the Parkview Health Ecosystem

6.1.1 Collaboration with Parkview Research Center

The Parkview Research Center (PRC) was instrumental in the successful completion of the research described in both Chapter 6 and Chapter 7. The Health Services and Informatics (HSI) group at PRC has a core focus in mental health. Within this scope, the HSI group is dedicated to exploring the use of technology and technological advancements to identify issues, increase access, and ultimately lessen the stigma and burden that surrounds the mental health community. Based on this focus and the goals of my dissertation research, this partnership was ideal to best execute this research. HSI embedded me into their unit, giving me access to the system that was otherwise unattainable which provided me valuable insights that was otherwise impossible. This knowledge and access were critical and greatly influenced aspects of the research design.

6.1.2 Collaboration with Parkview Providers

Parkview Physicians Group (PPG) is comprised of approximately 1550 providers spanning more than 45 clinical specialties providing services in 318 locations across Indiana and Ohio. The PPG Psychiatry team of providers specialize in emotional and behavioral health and offer a wide range of both outpatient and inpatient services. Dr. Alycia Brown, MD was the clinical partner in the research conducted at Parkview Health. The Executive Committee for PPG-Psychiatry reviewed the research protocol and approved Dr. Brown's participation in addition to communicating positive feedback on the study design and goals.

Another critical partner within PPG was Parkview Behavioral Health (PBH). PBH is a critical connective point within the system as it relates to connecting patients to mental and behavioral health services. PBH works with PPG-Psychiatry clinicians, behavioral health providers, and community partners to provide comprehensive services to those in need. PBH also provides northeast Indiana's only inpatient mental health services for children and adolescents. In addition to the support of PPG-Psychiatry, this work was supported by the Kevin Murphy, MD, PhD, the Medical Director of Parkview Behavioral Health and Connie Kerrigan, MBA, BSN, RN the Director of Outreach for Parkview Behavioral Health.

6.1.3 Collaboration with Community Partners

With the assistance of PRC and PBH, I forged partnerships with a local nutritionist and a specialty counseling center that specializes in eating disorders. The research proposed for this dissertation in partnership with Parkview was reviewed by Ann Reidenbach, MPH, RDN, CD, a Nutrition Therapist in the Fort Wayne Community and a trusted partner of

Parkview Health. By partnering with additional community partners, this research samples healthcare providers from the entire spectrum of clinical care.

6.2 Healthcare Provider Understanding of Digital Self-Harm

The HCI research within this dissertation and within the field highlight how online and mobile technologies are used in relation to digital self-harm indicators, behaviors, and activities. In order to understand the clinical contexts of eating disorders and social media, in this chapter I compare healthcare providers' experiences with patients' disclosure of social media use in connection to their disease and their perceptions of the impacts of social media on patients' mental health. Understanding the clinical processes that patients encounter and how disclosures of technology use and impact associated with their eating disorders is a critical component in understanding how digital self-harm could be addressed in the future.

6.2.1 Background

Assessing eating disorders in a clinical setting can take various forms depending on the type of healthcare provider that the patient engages. Providers can range from pediatricians, dietitians, clinical psychologists, therapists, family counselors and clinical social workers. Certifications are also available to practicing providers. Treatments are usually based on the criticality (if patients are not medically stable, hospitalization is often the first step of treatment). In-patient, outpatient, and residential care may be warranted.

Diagnostic tools. There are several key validated instruments that give healthcare professionals high-level information related to symptoms related to eating disorders like

eating habits, body-image and self-esteem issues, sleep patterns, and physiological issues like menstruation patterns. Eating Attitudes Test (EAT-26) is a widely used standardized self-report measure of several common symptoms. Additionally, it was one of the first tools that examine socio-cultural factors in the understanding of how an individual develops an eating disorder and how those factors play into the ongoing chronic condition [89]. This tool has been particularly successful in highlighting levels of risk within individuals with eating disorders [90]. The SCOFF Questionnaire (SCOFF) is a simple shorthand for Sick, Control, One stone, Fat, and Food. Additionally, it inquires about the satisfaction of eating patterns and if any secrecy is involved in eating habits [165]. At the time of its development, there was no simple, memorable screening instrument available for non-specialists. This tool was designed to help raise suspicion that an eating disorder might exist outside of specialized clinical assessment [115]. The Eating Disorder Examination Questionnaire (EDE-Q) is a self-report version of the interview-based Eating Disorder Examination [76]. The sub-scales of this tool focus on restraint and concerns associated with eating, body shape and weight and has found increasing popularity within research focused on bariatric surgery patients [104]. While some of these diagnostic tools take into consideration social factors, none take into consideration the use of technology in understanding the various influences of a patient's diseased behavior(s).

Technology Use. The focus of technology use within the realm of eating disorders has primarily focused on how technology enhances the delivery of ED treatment [229] and the positive impact on the effectiveness of technology-based interventions [8,36,180]. With the pervasive use of social media platforms in youth and young adult populations [232] and the rise of mental health issues within this population [74], research is focusing on the

impacts of social media use on mental health [31,53,124,163,186] and how certain mental health behaviors spread through social networks [227]. Social media as data source for population and individual health shows promise as they provide access to naturalistic accounts of an individual user's thoughts, feelings, and behaviors potentially indicative of current emotional states and wellbeing [56]. While using social media data for mental health shows promise, the promise must be appropriately tempered by the limitations of social media data like purposeful identity play [16], evolving language variation [40], and structural aspects of the platforms that limit the full spectrum of what could be shared through the social media platforms [167].

6.2.2 Methods

For this research, I designed an interview study to investigate clinical perspectives of technology use associated with their patients' eating disorders. Working with the partnerships outlined in Section 6.1, we recruited ten healthcare professionals to participate in the study using direct recruitment and snowball sampling techniques. Healthcare providers were recruited from the northeast Indiana region. While I worked with Parkview for provider recruitment, providers did not have to be employed by Parkview Health. Inclusion criteria for these participants included that they were a practicing healthcare professional, over the age of 21, work with patients exhibiting eating disordered behaviors or have been clinically assessed to have an eating disorder. Participants were recruited between February 2018 and May 2018. Table 6-1 highlights participant demographics.

The interview data was analyzed using thematic open coding. Two researchers reviewed three interview transcripts and developed an initial set of themes. They met twice to discuss

discrepancies and developed an initial set of codes. The researchers used this code book and completed coding all transcripts. Upon completion, the researchers obtained an 88.5% inter-rater reliability.

Table 6-1. ED Healthcare Provider Demographics

ID	Type of Provider	Years in practice	EDs Seen in Practice	Avg. Age of ED patients	Use of Validated Instruments for Diagnosis
P01	Psychiatrist	20-30	Bulimia, Anorexia, OSFED	Teens / early adult	No
P02	Therapist	0-5	All	Teens / Young Adult	No
P03	RN	20-30	Anorexia, Binging	Teens / Young Adult	No
P04	RN	20-30	Anorexia, Bulimia	Teens / Young Adult	No
P05	Dietician, Family Therapist	0-5	Anorexia, Bulimia, Binging	Teens / Young Adults	No
P06	LCSW	10-15	All	Teens	No
P10	LCSW	5-10	Bulimia, Anorexia, Over exercising	Early – mid 20sll	No
P11	Pediatrician	30+	Overeating, Anorexia, Bulimia, Body Image distortion	Teens	No
P12	RN	20-30	Overeating, Anorexia, Bulimia, Body Image distortion	Teens	No

P13	Family Therapist	30+	Binging, OSFED	Teens / Young Adults	No
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Interviews ranged from 35-70 minutes. They were conducted in the healthcare provider's office. All interviews were audio recorded and transcribed for analysis. While the providers were not paid for their time, I provided each participant with a small thank you gift which included a travel coffee mug and other small gifts for a total value of approximately \$25.00

The transcriptions were analyzed using an inductive thematic approach. Two researchers reviewed the transcriptions independently creating an initial set of themes then met to discuss similarities and differences in themes. One researcher had a background in HCI and one had a background in public health which was purposeful by design to ensure that different perspectives would be reflected within the analysis. Consensus was reached and the transcripts were re-analyzed using the refined code book. When questions came up during the coding, the researchers met to discuss the issue and came to a consensus on the few case-by-case instances of uncertainty in the coding of the data.

6.2.3 Findings

The interview focused on clinical approaches to assessing behavior, characterizations of their patients, and how patients describe technology use in relation to their eating disorder in the clinical setting.

Approaches to assessment. During the interviews, none of the providers indicated that they used validated instruments like the EAT-26, SCOFF, or EDE-Q. When asked, several

of the providers indicated that they knew about these tools, but they were not integrated into their assessment process. P07 shared *“So I actually don’t use standardized tools in my assessment. I probably should, but I don’t.”* None of the providers gave a reason or rationale for why they did not use one of the various standardized screeners during the assessment process.

While most of the providers described individual approaches to assessment, several of the providers talked about using a standardized process developed within their specific practice. Regardless of if it was an individualized or shared practice process, the assessments all included some form of biological, psycho, and social approach. P04 expressed this as *“allowing the patient to tell his or her story. It’s a history of the onset of the disordered eating thinking and how that flowed into other behaviors, how it accelerated the behaviors, and what has driven that patient to my office.”*

Several providers discussed customizing their approach to standard assessment procedure. Only one provider discussed asking patients about social media or technology use as part of assessing the patients’ eating disordered behavior: *“It’s typically part of my assessment. I just talk about it because it is part of their life, so it’s important to ask when assessing the influences and disease-related supports”* P04. Another provider discussed that the varying ages of their patients led to modifications of the practice assessment, *“I pretty much ask all the same questions. If it’s age appropriate, like a 9-year-old, I’m not going say so have you been sexually abused. In this case, I modify my approach for the child, but basically the same information we’re looking for”* P05.

Common influential aspects of eating disorders. There is a myriad of various influences identified by the providers. These influences are often interconnected and difficult to disentangle. P05 talked about this interconnectedness,

“I always say it’s like a stew, that you could put in some genetics, other mental health issues like anxiety and, depression (which can also be genetically motivated), familial environments and societal pressures. Additional aspects include trauma and technology – depending on the age” P05.

The family environment was the most common influence as it was mentioned by all participants. P10 shared that *“A lot of conflict with the mother seems to be pretty common across my patients recently.”* P04 discussed dysfunctional family relationships not just between immediate patient and parental figures but also within the larger family network. These familial issues were also brought up as one of the most challenging aspects for treatment and ongoing recovery. P05 discussed that patients with a “less intact family unit” are often the hardest to treat and are more at risk because, *“they don’t have that solid base, so they’re reaching for something and [what they eat] is something that they can control.”* Family patterns are also difficult to address as the patient is only one component of the family unit: even if they are trying to resolve issues, there could be other family member issues impacting their environment that is out of their control.

Social influences were also one of the more popular influences shared by the providers. Participants talked about social influences at the local level (e.g. friends, peers, school mates) and the societal level. For the societal level, they discussed traditional influences (e.g. magazines, movie stars, televisions) and online influences (e.g. websites and social

media). With regards to the online influences, there was a diverse set of thoughts related to social media as a causal factor. P06 shared, *“Social media, I think that oftentimes that's not necessarily a causal factor. It's the thing that pulled the trigger kind of thing. There's already some underlying things going on and then there's an experience going on.”* Yet this is a contentious point within the participants. P13 refuted this sentiment when recalling the role of social media on a past patient, *“She would purge, then for a while she would binge, and then she would purge again. Social media fueled this process.”* Some also believe that social media is only an issue for certain groups of patients. When discussing social influences, P04 only saw social media as an influence of youth and less of an issue for adults.

Social media was also seen as a space that reinforced eating disordered behaviors, especially within youth and teens. P01 reflects that eating disorders, especially Anorexia, tend to be ego centric. By sharing with people on social media or just being part of those discussions, it is easy for patients to have their diseased thoughts and behaviors reinforced through their social media activity.

Expected ED behaviors online. A component of the interviews focused on having the participants reflect on what types of disordered behaviors they would expect to see on social media. The most popular response was diets. Providers believe that social media is a powerful tool in sharing how to restrict, hide, and decrease caloric intake. In addition to diets, exercise regimens like CrossFit can also be harmful. P06 mentioned this and discussed the challenges of understanding at what point this was a healthy lifestyle or being weaponized within their disease. Another aspect of social media is the sharing of images and video. P04 discussed media sharing associated with life events like spring break

photos. They discussed how patients had looked for thinspiration online to help support their diseased thoughts and behaviors.

Patients disclosing social media activities. All providers discussed patients talking about their online activities. Only P05 directly asks their patients about social media activities. In all other cases, the patient typically brings up activities or discloses issues without prompt from the provider. P11 has seen an increase of their patients talking about online activities in the last several years – online activities were rarely [if ever] discussed throughout the first 20 years of their practice. P10 sees online activities come up naturally during the therapeutic process, *“It usually comes out in discussion, some more than others, like definitely the high school and college students who are impacted the most.”* The most popular social media platforms mentioned in therapeutic context are Instagram, SnapChat, YouTube, and Facebook. Providers also talked about wearables like Fitbits and text messaging being problematic for their patients.

The role of social media in the disease. The providers were polarized in their thoughts about the role of social media as it relates to their patients’ eating disorders. Two of the providers discussed the positive influence of these platforms as a recovery support tool. P04 still uses a private Facebook Group for support groups. They also discussed the use other technologies with their patients, like Recovery Road. P02 also describes the power of breaking isolation. Patients who are extremely ill to the point of self-isolation, social media and connections made through the Internet are often their only social experience.

Providers across the board felt that social media had a role to play within their patients' eating disorders. The most popular concern was the influence of these platforms on their patients. P04 elaborates,

“Instagram, Facebook, Snapchat – I see that as being pretty profound as compared to going to specific websites that talk about dieting or something else. I see [these platforms] as powerfully influencing, and their smartphone is with them at all times, so there is no escaping it. The images are the most damaging – seeing what other people want you to think is their life. It falls back into what they think about themselves. Why isn't that my life, why wasn't I invited. And then they start questioning themselves. Are they liked? That kind of thing can fuel self-doubt and undermine their inner-strength”

Another example of influence of this is feeding into already altered perceptions – especially with Anorexic patients. P05 discussed the curated posts people will contrive that is an illusion, and patients with altered perceptions have difficulty or are unable to critically analyze these posts as anything except for reality.

Providers also discussed the way social media can be weaponized as a medium for hate and bullying. P04 shares, *“People can be very mean online – they might communicate something that they would never say face-to-face and that can influence how someone thinks and feels about themselves.”* P12 bolsters this influence, *“Bullying is a huge deal with this population – be it anorexia, compulsive behavior, or body image distortion. So yeah, bullying is a big deal with them.”* When an individual is already in a compromised emotional state in relation to their body, having

active online attacks focused on these attributes can further exacerbate these negative thoughts associated with their eating disorder.

6.2.4 Discussion

Common tropes associated with youth and social media were present across the various participants. P13 discussed the patient not utilizing social media because the parents took it away from him. While this could be true, research shows that teens can have multiple accounts on a platform of which one is specifically for parents [118,207], that parents might not even know the various platforms being used [192], and underestimate the amount of time youth spend engaged with technology [22]. Additionally, all of the providers talked about social media use and its impacts as an action of their more youthful patients. While this is most likely realistic within their patient populations, it is an assumption that could further alienate and overlook potential influences associated with their older patients. Research indicates an increase of internet use and its impacts on wellbeing of older adults [17,114].

Regardless of their assessment of or direct engagement of social media use, all providers discussed the impacts of social media on people with eating disorders. They identified key aspects of exposure and reinforcement being the most troublesome. Unlike traditional media influences like magazines and video, social media combines these aspects of traditional media with technologically mediated peer interactions. This combination of visual media and propagation of stereotypes among peers may be linked to increased risk for eating concerns [239]. These assessments from the providers uphold various research

findings that show that common, non-maladaptive use of social media can be associated with disordered eating issues [146] and that a strong association between social media and eating disorders is present regardless of the frequency of use [230].

The interviews shed light on an interesting tension within the various providers and their assessment processes: regardless of role, social media use is viewed as a negative impact on patients with eating disorders yet only 10% of the sample actively engage their patients on their social media use. When technology use is brought up by patients, most of the providers treat the social media issue as a singular event – not something that is ongoing or pervasive in their patients’ life. When reviewing the diagnostic screeners – which none of the providers used – it was evident that these tools only take into consideration influences and impacts of an individual’s home and school/workplace or as Oldenburg would call them first and second place [184]. Oldenburg defines third places as social-centric environments like libraries, churches, and parks. Even collaborative events like bowling leagues have been defined within this concept [209]. Most recently, computer-mediated spaces like social media have been defined as a “third” space [233]. Thinking of online spaces where patients engage with or create content that negatively impacts their health as it relates to their eating disorder as a “third” space is critical for treatment. If online engagements are thought of as a singular event and not something that is more persistent and continuous, any treatments associated with online engagements will potentially fall short of addressing the root issues associated with online activities.

As indicated by the participating providers, there is probably a need to assess online engagements and influences the same way that current diagnostic tools assess environmental influences. There are tensions related to integrating social media data into

the clinical setting. From the healthcare perspective, there are issues related to privacy – especially related to protected health information (PHI) and Health Insurance Portability and Accountability Act (HIPAA). When asked if they would want to use social media data in their assessment or ongoing treatment of an individual, several of the providers in this study raised questions about the integrity of the social media data: how do you verify that the individual patient being seen actually created this content and how reliable is this data (is it an actual account of symptomology or are there attention seeking reasons behind content). One provider went even further to discuss that if it was even ethical and physically possible for them to obtain this data, what is the legal and ethical responsibility they will now incur by integrating this type of patient data into their practice's standard of care. Integration of healthcare into social medias as a tool for health communication is already fraught with challenges and tensions [34,255] let alone introducing a patient's specific social media content into their health record.

6.2.5 Conclusion

Social media use by patients with an eating disorder is a complicated issue, both for the patient and the provider. Simply creating diagnostic tools for providers to use that incorporate technology habits and behaviors is not enough as witnessed by this cohort of providers who do not use specific eating-disordered screeners. Collaborations with healthcare providers is essential to understand what is needed from a communications and continuing education perspective as it relates to the technical platforms used by patients, what the technical affordances allow, and what common behaviors are found within these platforms as it relates to eating disorders. Furthermore, additional work is needed within

the social computing domain to understand the impacts of social media on individual patients and not just at the population level.

CHAPTER 7. ASSESSING DIGITAL SELF-HARM WITH PATIENTS

As outlined in previous chapters, assessing digital self-harm behaviors with a population of clinically diagnosed patients is paramount in providing ground truth, bridging the knowledge base developed using public data with a defined population of patients with a clinically diagnosed eating disorder. In this chapter, I highlight how patients use social media and social technologies in relation to their eating disorder. In this process, I validate and challenge critical findings from previous work. Finally, I provide design recommendations for social media platforms generated based on my interviews with patients and longitudinal reviews of their social media activity across multiple platforms.

7.1 Background

Understanding the motivation for individual social media use can be challenging. It is most commonly assessed through the use of models and tools focused on text mining and linguistic analysis. Less common approaches directly engage the individual, having them reflect retrospectively on why they posted specific content [274] or why they searched for this specific content [139]. Having a deeper context to activities and findings has proven to be an important factor within the health [244] and social computing [7,195] domains.

Recent scholarship has focused on using sophisticated computing techniques to infer or detect an individual's mental health status. This research has focused on mental health issues like depression [18,48,50,204,214], suicidality [51], anxiety [228], schizophrenia [20] and more general mental health [49]. These studies use a variety of computational

methods, including topic modeling, machine learning, and language and interaction measures to assess patterns that are then transformed into models of behavior. The availability of online public data allows researchers to curate large datasets and apply these methods to understand certain health conditions. While these studies provide a broader understanding of how mental health statuses are presented and change on social media platforms, there are several limitations to these methodological approaches. The primary limitation is that it is not possible to confirm the actual disease state of the individual content creators. Also, many of these studies focus on a singular platform rather than survey across platforms. Even though there are some generalizations that can be made across platforms, there are specific norms and community standards that influence or constrain what individuals post in these channels.

7.2 Methods

I designed a mixed-methods study that included surveys, participant interviews, and social media analysis to investigate how patients used technology in relation to their eating disordered behaviors and the perceived impact of these engagements on their mental health. I present this study within the format of a set of case studies. I chose this approach for several reasons: case studies can facilitate the exploration of a phenomenon utilizing various data sources [15], can provide contextually rich descriptions [222], and can help define or expand theoretical constructs [70].

Recruitment. I worked with physicians at Parkview Health and local healthcare providers to recruit patients for this study as it was recommended by our IRB that we have clinicians within our community recruit for our study, as they were the best arbiters of if

the patients were stable in their recovery - a key requirement for our inclusion criteria based on the sensitive nature of the mental health issues assessed through the research. These clinical psychologists, dietitians, pediatricians, and therapists identified patients whom, in their professional opinions, were stable in their recovery and would be at minimal risk and who also met the following criteria: were over the age of 13 (if under 18, had to have parental consent), be referred to the study by a healthcare professional that had reviewed their chart or have been referred to the study by another individual, but allow researchers to contact their clinician and access their medical records), no previous suicidal attempt or ideation for the past 12 months, have not had more than two relapses of eating disorder symptoms (e.g. bingeing, purging, restricting) in the past 6 months, had received or was currently receiving care from a healthcare professional to address eating disorder behaviors, and allow researchers to obtain general information about the eating disorder activities/behaviors from referring healthcare provider and their electronic health record. The patients were given the contact information of the research team and had to initiate communication with them to start the screening process. Once the patient contacted the research team and gave permission for the team to access their medical records, a clinical psychologist reviewed the medical record to ensure they fit the inclusion criteria. Patients were recruited between March 2018 - July 2018. The full IRB protocol is located in Appendix D.

Participants. Three women were recruited by the partnering clinicians to participate in this study. The average current age was 25.0 and the average age of initial eating disorder onset was 15.6 years old. All participants were high school graduates. All participants reported using social media platforms and other mobile fitness applications during the

height of their disease. All participants agreed to give us access to their social media data. Based on the inclusion criteria, all participants reported having been stable in their recovery for at least a full year at the time of their participation. The surveys and interviews took place in Spring of 2018. Participants were given a Visa gift card for \$35.00 for their participation. To derive the amount for compensation, we took the May 2017 average for service providers from our local area from the US Bureau of Labor and Statistics which equated to \$13.30/hour [250]. The estimated a range of time for participation at 2-2.5 hours for both the surveys and the interview. This estimate equated to \$33.25 for participation therefore the stipend amount rounded to \$35.00. Participants were paid upon the completion of the interview.

Data Collection. Prior to the interview, we distributed three surveys to the participants using the Survey Monkey platform. The first survey was a technology user and behaviors survey that from a past study focused on assessing the online behaviors of adolescents and young adults [196]. The second survey was the RAND 36-Item Health Survey 1.0 (RAND-36) [112] which is identical to the Medical Outcomes Study Questionnaire Short Form 36 Health Survey (SF-36) except for the way the results are interpreted. This patient-reported tool focuses on assessing patient health through a series of dimensions including physical functioning, role limitations due to physical and emotional issues, energy/fatigue, social functioning, pain, general health, and health change [261]. The third survey was the Patient Health Questionnaire-4 (PHQ-4), a brief screening scale for anxiety and depression [133].

Upon the completion of the interview, patients were asked if they wanted to opt in for the social media analysis component of the study. The only accounts participants reported using prior to their first recovery point were Facebook and Instagram. Once access was

given, the first author manually reviewed and collected 18 months of data prior to the point they identified as being in recovery as there is no active API that could be used to pull this data. Points beyond that initial recovery would be harder to compare against each other because the access to social media could be highly varied based on the type of recovery path taken. For example, one patient could have been in an intensive 90-day inpatient treatment with no access to technology while one patient could have been working with an outpatient program that would allow them to continue their social media use if they wanted. Additionally, recovery is not a linear path, multiple relapses and recovery periods are common in this population. Because of this variability, we chose to focus solely on the period leading up to their initial recovery.

Data Analysis. I analyzed the surveys based on the appropriate measures. The technology inventory does not have an analysis key as it is used to report basic utilization patterns. The PHQ-4 items are scored based on scale from 0-3. Scores are rated as normal (0-2), mild (3-5), moderate (6-8), and severe (9-12) [133]. The SF-36 was analyzed using the RAND-36 method. This scoring approach is a simpler and more straightforward approach and has been validated [112].

I took a deductive approach to the qualitative coding of the social media data. We began with the media codebook from Chapter 5 that was designed to assess eating disorder-related online content [195]. I then took an inductive, iterative approach to coding the data and growing the codebook as it made sense for the data. A team of two researchers met several times to discuss the coding of data and new parent and/or child codes needed for the analysis. Table 7-1 displays the final code book, highlighting the new additions for this analysis.

Table 7-1. Media Codebook

Parent Codes	Existing Child Codes	New Child Codes
Image Qualities	black and white, color, drawing, image (group, individual, other), selfie, video	image (animal, object, place), collage
Image Mood	angry, artistic, happy, inspirational, neutral, painful, provocative	informational, inquisitive, humorous
Identifiable	yes, no	
Body Part	arm, back, breast/chest, butt, collar, face, feet, full body, hands, head, hip, legs, neck, ribs, shoulder, stomach, thigh, torso, waist	
Text Mood	emotional-negative, emotional-positive, inspirational, neutral, no text	celebratory, emoji, health (mental, physical), humorous, inquisitive, reflection (internal, external, both)
Hashtag/Text	emotional (positive, negative), inspiration, neutral, no text	celebratory, emoji, health (mental, physical), humorous, inquisitive, reflection (internal, external, both)
Point-of-View (New)		internal, external, both internal and external

To quantitatively assess the sentiment of the social media data collected from the patients' accounts, we chose to use the Linguistic Inquiry and Word Count (LIWC2015) software [205], a practice common within previous HCI research on social media content [39,45,47,204]. This approach allows for us to systematically and objectively analyze the

Facebook and Instagram posts for specific emotional components using LIWC's psychometrically validated internal dictionary

7.3 Findings

For each case study, I give a brief description of the participant and how they came to start their recovery journey. This data came from the demographic survey and their interview. Second, I review the mental health indicators for the participants which is derived from responses on the PHQ-4 survey, RAND-36 survey and interview data. Third, I review their general technology use and technology use in relation to their eating disorder using data from the technology survey, interview data, and their social media content. Finally, I discuss the technology's perceived impact on their disease which is derived from their interview and social media data.

7.3.1 Case Study 1: Margarita

Margarita is a 28-year-old Caucasian, Non-Hispanic female. She lives in a rural town with a poverty rate between 10-20%. She recalls her eating disorder behaviors beginning in the summer leading into her freshman year of high school. Her recovery started during her sophomore year at college. She believes that her dietician, who has a therapeutic approach, helped her the most in her recovery. Margarita believes that she treated her in a holistic manner, not focusing just on her diet and eating, but also inquiring about other things that she would pick up on during their interactions.

Mental Health Indicators. Margarita scored a 1 on her PHQ-4 which puts her in the "normal" range. Her RAND-36 scores show that she had slight elevations with limitations due to emotional problems (66.7%), energy/fatigue issues (60.0%), and emotional well-being (72.0%). Her general health score was 70%. The major individual issues that were pertinent included that she accomplished less than she would have liked, and she does not believe she is as healthy as anybody else she knows.

She suffered from anorexia, but also had tendencies for compulsive exercise. Her eating disordered behaviors started the summer before high school - she recalls "*wanting to lose 10lbs so that her thighs wouldn't touch.*" It started innocently, eating "healthier" foods and watching her portions. She stated checking her weight more frequently as the summer progressed. It was during a sports camp at the end of the summer, that she noticed that she was getting into an unhealthy routine where she would not eat, go to practice, come home and shower/sleep all day, eat a Lean Cuisine, go to her second practice, not eat, shower and go to sleep. Upon reflection, this is the point where she "*noticed my mind starting to change.*" She began to "freak out" about small things and felt lonely and sad all the time. She had dropped so much weight and was struggling in her sport that her parents began to worry about her health and took her to a dietician and a therapist. Even though she was seeing clinicians at this time, she does not feel like she was in recovery. She was still struggling with her ED even though she was eating more, she was still very conscious and obsessive: "*I would get enough calories, but it would be the bare minimum because I wanted to be at the bare minimum of my weight chart that I could be at.*" During the height of her illness, she thought about her eating disorder all the time stating, "*I couldn't escape it.*"

Technology Use. Margarita is highly connected as demonstrated through her survey responses: she has a home computer, smartphone, and ubiquitous internet connectivity. She also uses her smartphone for a variety of activities: text messages, internet surfing, photo/audio/video sharing, consuming audio/video, and playing games. She uses her computer mainly at home. She uses her smartphone most frequently to access the web. When she is not physically with her friends or family, she prefers to connect with them through text messages. Her social media data is also quite diverse. She reports regularly visiting Facebook, Instagram, YouTube, Pinterest, and SnapChat. She primarily uses these platforms to keep in touch with relatives and friends who live far away, to talk to friends, and download/upload photos/videos. Margarita reported that her interactions online have influenced her to buy or wear something or go somewhere, has tried to get someone else to buy or wear something or go somewhere, and that she felt pressured to share something that she would not normally share. Through her online interactions she has never felt bullied. She reported that she feels there is not a difference between her online and offline self and that her online “reflects the real me.”

Margarita shared her Facebook and Instagram data. During this period of time, she posted 1,228 posts or pieces of content. Even though the Facebook platform allows for posts with just text, all of her Facebook posts contained a piece of media (video or image). While Margarita's network actively likes her content (average 65.4, range 0-265), there is a much lower active engagement as measured by comments on her content (average 2.1, SD=3.11). Table 7-2 highlights the specifics of her data. The frequency of Margarita's posting follows a specific pattern: her activity would increase for several months, followed

by a sharp decline for several months. This pattern is consistent across the entire 18-month period leading up to start of her initial recovery (see Fig.7-1).

Table 7-2. Characteristics of Social Media Activity: Margarita

<u>Breakdown of Posts</u>		<u>Type of Posts</u>	
Facebook	1142	Text only	0
Instagram	86	Text + Image	127
		Image Only	1063
<u>Post metadata</u>		Relationship Status	1
Avg. likes/post	65.4	Links	9
Avg. comments/post	2.1	Videos	17
% posts w/hashtags	7.9		

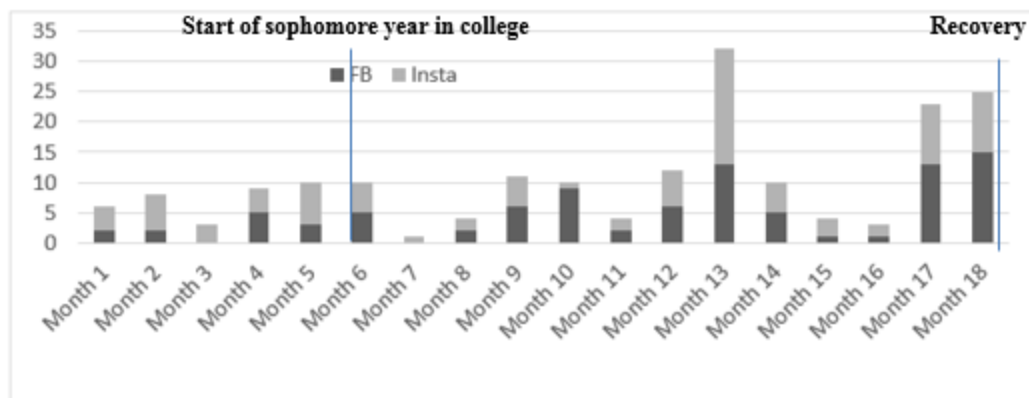


Figure 7-1. Social Media Data Over Time – Margarita

The LIWC analysis of Margarita's social media posts indicated that the content showed more positive than negative affect (8.1 vs 0.9, respectively) with her positive affect actually increasing throughout the duration of the time period assessed (Months 1-5, 7.90; Months 6-12, 7.9; Months 13-18, 8.4). She talked very infrequently about her body (0.3) and her health (0.1). A majority of her posts focused on the present (6.9) vs looking back to the past (1.6) or to the future (1.1). The LIWC assessment also showed very little content associated with personal insight (1.0).

The qualitative assessment using the codebook resulted in a more nuanced and holistic understanding of her perceived identity - the posts, text, and media were coded. For example, Margarita did not discuss anything associated with her physical health, inspiration, or inquisitiveness. Of the posts that had text associated with them, 38.1% of the posts were labeled as emotionally positive, 35.8% celebratory, and 29.9% neutral. Over half (56.7%) of posts had an emoji embedded in the post text. The point-of-view (POV), measured as either internal, external, or both, resulted in a particularly interesting result. In the year preceding the start of her recovery, Margarita began reducing content that focused on herself from her social media streams and increased the amount of content that focused on friends and family. The Figure 7-2 highlights exemplar social media posts that embody this concept. Figure 7-3 shows the interplay of internal and external content over the period of analysis.

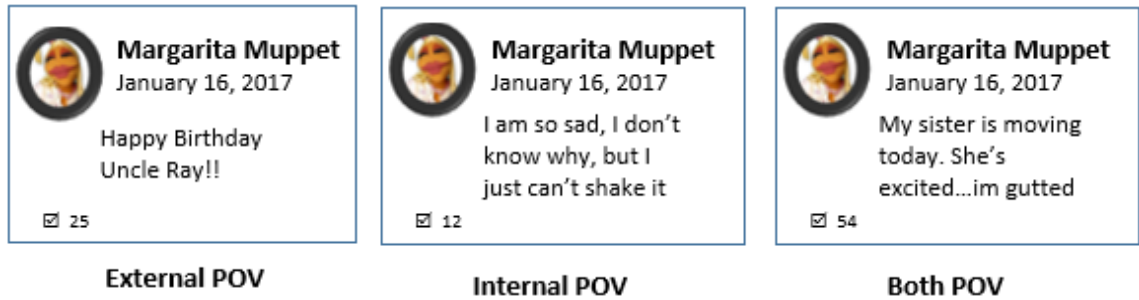


Figure 7-2. Exemplar Point-of-View Social Media Posts – Margarita

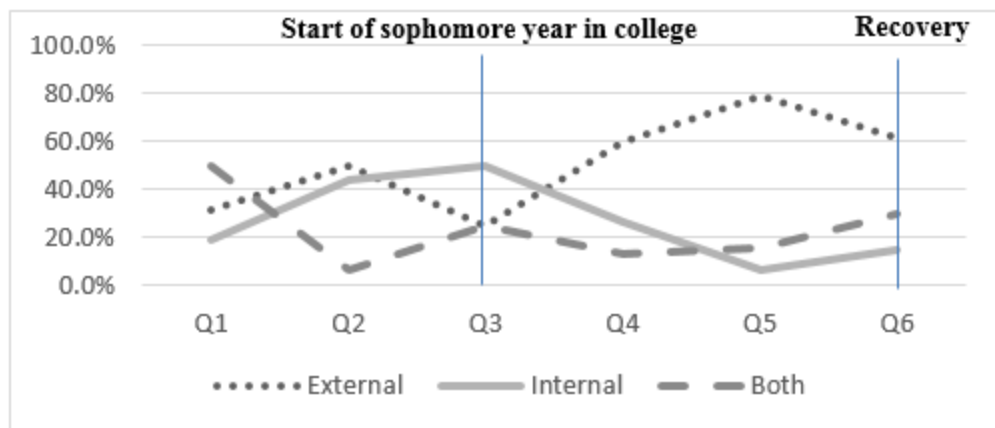


Figure 7-3. Point of View of Posts over Time – Margarita

The media shared on Margarita's accounts overwhelmingly featured herself - her likeness was identifiable in 70.2% of the media. In the media where she is visible, the most common aspects of her identity are her full body (44.1%) or her face (65.6%). This is to be expected as they are common poses for pictures. Almost equal amounts of media focused on family (34.3%) and friends (31.4%). Out of the 1,228 pieces of media shared, there were no images that depicted certain "Thinspiration" as found Chapter 4 [40] and Chapter 5

[195]. The media found in her social streams reflected the typical media of teenager: images of friends, family, vacations/trips, and milestones like prom and graduation.

Technology Use in Relation to their Eating Disorder. During her interview, Margarita reported that she had used social media platforms to access extreme weight loss or eating disorder-related content but had never posted content related to her eating disorder. While she accesses this information, she did not feel influenced by what she was seeing. She reports that she has not accessed disordered content online since being in recovery. She does not have a separate social media account for her online eating disorder activities. Her parents, caregivers, and healthcare providers have never inquired about her use of technology related to her eating disorder.

Margarita's preferred technologies during this time were MyFitnessPal and Tumblr. These were her consistent platforms. She used Facebook initially but stopped using it as frequently when her account was hacked as a freshman in high school. Twitter and Instagram were also part of this portfolio. Additionally, she talked about using recipe apps like Taste of Home and Whole Foods to find lower calorie, fat-free options and recipes. She reports that she used Twitter and Facebook daily. Fitness apps and MyFitnessPal were “always on” and she likened it “*those kids [you see] playing games all day on their phones, that was me in those apps.*” She reports having just one singular profile on these platforms - she did not create specific profiles for her disordered activities and behaviors.

She shared that Tumblr was the only platform where she encountered specific eating disordered content online. She said that she probably did search for content using specific terms but can't remember what they were. When viewing this content, she recalls seeing

hashtags within the content, clicking on these, and being exposed to disorder-related content that was beyond the initial search content. This type of secondary exposure to potentially triggering content was common for her to consume. The main draw for Margarita was meal prep and quotes. She reported, for her, it was less about pictures and more about the text content. The pictures that she preferred were those that had quotes on them. She shared that they were pro-ana quotes/words/phrases associated with pictures of girls who were really thin. She would look at this type of content a few times during the day, but definitely more on the weekends.

While on Tumblr, Margarita talked about following certain accounts that were pro-ED. While she consumed content, she never created any content. She would often write in a journal, as she found writing easier than talking about her disorder. She reflected that she is still closed off about feelings for a variety of different things,

“In that moment, I didn't want to tell people because I didn't want them to know I was struggling. It was a very scary, private thing for me. I didn't want to put that burden on someone else.”

She discussed not wanting to burden others in both the online and offline context. However, there was a disconnect for her related to her engagement with online content. While not creating content, she would sometimes “like” a post in her Instagram and Facebook feeds. She described this activity as an internal process, something that she could see as she scrolled through her personal feed. However, she did not discuss the social cue or signal that liking a post sends to the original poster.

Technology's Perceived Impact on their Eating Disorder. Margarita was very clear about the impact of technology on her eating disorder. She recalls sitting in study hall estimating the calories of the lunches her mother would pack for her. She would use her smartphone to take notes, paying close attention to the fat and caloric intake. Then she started using MyFitnessPal. Upon bringing this up, she paused and then stated, *"I hate that app."* She found the app while looking up weight loss supports in the app store. She reports spending hours on her phone looking up these apps and looking at recipes trying to make things even more reduced fat and calorie. She mentions that using this app was like ***"throwing gasoline on [her] eating disorder - everything went to a whole new level when [she] started using it."*** With respect to the pro-ana content that she was finding on Tumblr, she reflected that looking at the content made her feel like she wasn't alone. She remembers thinking, ***"If other girls are doing it, like what's the big deal. Like, I'm not going to die."***

Margarita's family knew about her obsessive relationship with MyFitnessPal and the nutrition apps because they would always see her using them. However, they did not know about the pro-ana engagement on social media platforms. During her recovery, none of the healthcare professionals that saw her asked about her technology use. She remembers discussing using MyFitnessPal with her dietician, especially when she was being argumentative, *"Like, my app says I don't need to eat that much."*

Through the assessment of her online social media data, only one post potentially focused on her eating disorder. In a post a few days before she started her recovery journey, she stated that she was *"hopeful that the next few months would be a time of transformation."* While we know from her self-report this was very close to the time of her recovery, it also coincided with a major milestone, her high school graduation. Our

research design did not allow us to ask her for clarification, but without the context of her interview and medical records, we would have used the context from her account to mark this as related to her recent graduation and not potentially a new outlook spurred by her eating disorder treatment.

When coding for the media archetypes found within previous research characterizing online eating disordered content, only three posts out of the 1228 (0.2%) were assessed to fit this framework: the diet archetype. None of the identified ED terminology from this previous research were found in the lexical analysis of the posts. This observation, combined with the lack of media archetypes and the LIWC analysis results, indicate that the current computational methods for finding and assessing online eating disordered content would not have identified Margarita as being at risk despite that she clearly was at risk during this time period as deduced through the review of her medical records and validated through her interview data.

Margarita transitioned her use of social media platforms once she began her recovery journey. She talked about unfollowing pro-ana accounts and starting to follow people that were in recovery. Here she reflects,

“They would post about their good days and they would post about their bad days and more about their feelings. It would kinda help me because I wasn't feeling so alone again, but in a different aspect of the disease. I started following this one, My Recovery Posts, where you can anonymously send stuff and talk about your struggles and people can reply and lift you up. So it kinda changed. But I was still

looking for quotes, but more motivation like 'don't wage war on yourself' or 'you don't have to be perfect.'"

For Margarita, looking at recovery posts and knowing that other people could do it affirmed that she could do it too.

7.3.2 Case Study 2: Sheila

Sheila is a 21-year-old Caucasian, Non-Hispanic female. She lives in a suburban town with a poverty rate between 3-5%. Sheila's symptoms began in her last year of middle school (8th grade) and continued until her junior year of college. Sheila's recovery began with an intervention. She then went to an intensive outpatient program where she saw a therapist for 3-4 hours each day. That time helped her illuminate the unhealthy beliefs she held and relearn healthier ones. She believes this process was the most critical aspect to sustain her recovery

Mental Health Indicators. She scored a 0 on her PHQ-4 which puts her in the "normal" range. Her RAND-36 scores show that she had slight elevations with limitations due energy/fatigue issues (55.0%), emotional well-being (80.0%) and social functioning (87.5%). Her general health score was 55.0%. There were no major individual issues that were pertinent positive.

Sheila considers herself a compulsive over-exerciser, but also struggled with disordered eating behaviors related to anorexia and bulimia. Her eating disorder behaviors began during high school. There was not a specific point that she can point to as the start

of her disordered eating as she did not even realize she had a problem. Once in college, her symptoms became more severe and she realized it had become “full-blown.” In her words,

“I can look back and see where it all began and all the things that led up to having a full-fledged eating disorder. So I wouldn't say it was one moment, but a culmination of things.”

During the height of her illness, she reports that she was battling eating disordered thoughts all the time - any time she had a thought to herself, it was there. Sheila had other health complications that she did not go into, but mentioned that during this time period she was being seen for a physical health condition.

Technology Use. Sheila's survey results indicate that she is highly connected: she has a home computer, smartphone, and ubiquitous internet connectivity. She also uses her smartphone for a variety of activities: text messages, internet surfing, photo/video sharing, consuming audio/video, and playing games. She uses her computer mainly at home. She uses her smartphone most frequently to access the web. When she is not physically with her friends or family, she prefers to connect with them through text messages. Her social media data is also quite diverse. She reports regularly visiting Facebook, Instagram, Twitter, Pinterest, and SnapChat. She primarily uses these platforms to keep in touch with relatives and friends who live far away and to download/upload photos/videos. Sheila reports that she has been bullied through texting or other online activities but declined to answer who she felt bullied by. She did not report about her different online influences. She reported that she feels there is not a difference between her online and offline self and that her online presence “reflects the real me.”

Sheila has no social media data to analyze. While she gave us permission to access her social media accounts, she informed us that there would be no data available. When asked if she continued to use social media once she got into treatment she responded,

“I stopped the Instagram account even before I went into treatment ... I’ve deleted my accounts when I felt they were hindering my recovery process. This is after actively [joining] recovery. When I felt better I would join back, but sometimes it’s just so hard to avoid that content because it is right there in your Instagram feed.”

She not only deleted Instagram and Facebook applications from her phone, but she also deleted her accounts on other platforms. When asked how many times she deleted all of her social media accounts, she responded: *“Quite a few. Nothing recently. I would say less than 10, more than 5. But that’s really just a guess. I deactivated them initially, but then started deleting them when I felt it was getting to be too much.”*

Technology Use in Relation to the Eating Disorder: With respect to her eating disorder, she reported that she had used social media platforms to access extreme weight loss or eating disorder-related content and had posted content related to her eating disorder. When she was in high school, she used MySpace and encountered what she now defines as cyberbullying while on that platform. During this time, she would *“use Tumblr to post or repost about her eating disorder, behaviors I was portraying, and feelings I felt due to my eating disorder.”* She has not been engaged in this type of behavior since her early high school years. She felt that the content she was consuming influenced her.

At one point when she was actively trying to lose weight, she created a separate weight loss account. She made sure that the account was private. She would use this account when

she was looking for specific media: she preferred looking at before and after pictures. She recounted that she found them to be extremely triggering, *“which is what I wanted.”* She also focused on content associated with Instagram fitness models because, just like the before and after pictures, consuming this content was triggering and made her feel bad about herself. She could not recall specific hashtags that were used in these searches. Other types of media like meal prep or inspirational quotes were not particularly impactful. Thinspiration media, more specifically images, were particularly of interest. Pinterest was another platform that fueled unhealthy behaviors. She would pin diet meals or workouts as a way to directly influence her disordered thinking and actions. Tumblr was another platform of interest. She never had an account on this platform but would use their open search function on the homepage. She comments, *“I would see the pictures. I would rarely actively search it out, but it was all over that place.”*

Sheila shared that she primarily consumed content in these various online spaces. Only on a rare occasion would she post something. She was asked if she also posted the types of before and after pictures that she found to be the most compelling in her consumption practices. At the thought of this she laughed, replying *“no, I don't think I had any before and after images that were worth sharing.”* The types of things she would post focused on regular activities, like going for a run. She never added hashtags to her posts because,

*“... deep down I didn't want anyone else struggling to finding it either. But I just felt that **I needed to get it out somehow** and I used the platform to do -- more like keep a diary ... but felt that without the hashtags it was a bit more low-key. I was very aware in my eating disorder that I had an eating disorder. **I knew how much***

it sucked and I didn't want to be the cause of anyone else being any worse. But, I still made the page, so ...”

Sheila was aware of the eating disorder specific language that is often used to tag these types of posts. She recalled a couple of times where she would click on a hashtag to check it out but would get “freaked out” by the content which led her to very rarely search on those tags. Upon entering treatment, Sheila deleted this account.

At the height of her illness, when she was in college, she reports using a variety of platforms including Facebook, Instagram, and Pinterest. She also talked about using BuzzFeed for different articles. With respect to mobile applications, she used an application that was similar to Weight Watchers in that it allowed her to track nutrition. She also used MyFitnessPal and MapMyRun. She used MyFitnessPal cyclically to track food and exercise. She would use it heavily for a few months, get to the point where she realized how toxic it was for her, stop using it, and then would restart after she felt less of the negative effects that caused her to stop using it in the first place.

Technology’s Perceived Impact on their Eating Disorder. Sheila believes that her engagement with mobile applications and social media played a distinct role in her disorder. The accessibility was a key factor. She was able to easily find information that validated and maintained her ongoing disordered thoughts and behaviors,

“The voice is so strong in your head and you want to make yourself feel bad. You [view] all of these posts and [are] like okay, this is how it should be because others were doing it. I was a lurker -- I would read other people's posts and comments and think ‘Oh, that's fine, I'm not that bad'. I used it as a tool to

convince myself that I wasn't as bad as these people or look how good this person is doing, maybe I need to do that good."

In her discussion about the impacts of her online activities in her daily life, she pointed out that it was highly variable for her: it depended on the moment and how she felt and how she was interpreting it. In a point of reflection, she stopped herself and offered, *"with one search you can find people who are struggling. It confirms you are not alone."*

During her treatment, none of her healthcare providers asked her about technology or social media use. Sheila did not have a primary care physician at the time. She remembers bringing up social media with her therapist but does not remember if it was discussed in any meaningful way.

With respect to support for her recovery, Sheila shared that she was very lucky - that almost all of her friends and family were supportive of her. She also used social media for her recovery as she would read articles on recovery and self-care and checkout websites like the National Eating Disorder Association. She particularly like reading posts about other's recovery journeys. She still consumes these types of posts. During her initial recovery, she used an app, Recovery Road. She found this app helpful, especially putting the emotions along with the eating habits so she could get a better grasp on it even though she expressed a reluctance at documenting her health status during recovery.

7.3.3 Case Study 3: Adina

Adina is a 26-year-old Caucasian, Non-Hispanic female. She lives in rural town with a poverty rate over 20%. The onset of Adina's eating disordered behaviors began when she

was 17, almost 18. She recalls being active in her disease for almost two full years. The genesis of Adina's recovery is different than the previous patients in this study. Similarly, her parents recognized there was a problem and took her to their family clinician. The clinician did not agree that Adina had an eating disorder. After confronting this issue, she soon began seeing a counselor and a nutritionist. Once away at college, she also ended up with a support team of a nutritionist and counselor. She would sometimes use Skype to connect with her home-based team while at school. She was finally accepted into an in-patient treatment facility. Her family were planning to take her out of school for this and were trying to pull the money together to cover the treatment facility when something *"snapped [her] to the recovery side."* She marks this time as the point where she started recovery.

Mental Health Indicators. Adina is highly connected: she has a home computer, smartphone, and ubiquitous internet connectivity. She also uses her smartphone for a variety of activities: text messages, internet surfing, photo/video sharing, consuming audio/video, and playing games. She uses her computer mainly at work. She uses her smartphone most frequently to access the web. When she is not physically with her friends or family she prefers to connect with them through online platforms like Instagram and Snapchat. Her social media data is also quite diverse. Included with Instagram and Snapchat, she frequently uses Facebook, YouTube and Pinterest. She primarily uses these platforms to talk to friends, keep in touch with relatives and friends who live far away and upload photos/videos. Her interactions online have influenced her to buy or wear something or go somewhere. Through her online interactions she reports having felt bullied through text or other online activities but doesn't know the identity of the person who

bullied her. She reported that she feels there is not a difference between her online and offline self and that her online presence “reflects the real me.” She included that “*while [my] posts are not calculated; they only show the 'highlight reel' of my life.*”

With respect to her eating disorder, she reported that she had used social media platforms to access extreme weight loss or eating disorder-related content and had posted content related to her eating disorder. However, the posting of ED-related content came with a disclaimer: she recalls using her “love for exercise” as a public reason she would share with friends and family as an excuse to use Instagram to look up content that fueled her eating disorder, for which unhealthy levels of exercise was a symptom of her eating disorder presentation. She recalls being heavily influenced by the content she would seek/engage.

She presented with anorexia and moved into binge eating as she neared the point of starting her recovery. She also struggled periodically with an unhealthy obsession with exercise. Her ED behaviors began when she was finishing high school, around 17 or 18 years old, during her final year of high school. There were a lot of things changing for her. The breakup of her relationship was a turning point. Upon talking about her relationship, she became quiet, retreating into herself for moment. She then shared that there were backhanded comments that “*messed with [her] head,*” things that made her feel awkward about her body. She said that “*[she] didn't know if he meant to say those things to her or if others meant to say things to her, but regardless it stuck with [her].*”

During the height of her illness, she reports that she was battling her ED symptoms on a daily basis. She restricted every day and when she “swung back to the binge side”, that

was every day as well. She recalls being in this heightened state for approximately two years.

Adina reflects on her ED journey as if in a dream - her memory is hazy and she has a hard time recalling certain aspects with clarity. In discussing her technology use, she also recalled that she didn't know she was restricting stating that she “didn't know what was going on.” When asked specifics about the use of a mobile application she struggled, “*I'm trying to remember. It's kinda fuzzy, that time.*” Upon the conclusion of the interview, Adina shared this with the team,

“I'm glad you are doing this. The medical staff needs to understand [eating disorders and technology] more, needs to know what to look for. Possibly it would have been caught at an earlier stage it could have helped with the deterioration of [my] mind.”

Technology Use. Technology is an integral part of Adina's everyday life. “Like everybody else I just scan [them] all of the time which is annoying to me.” Instagram and Facebook are the main platforms she uses. She uses Snapchat, Pinterest, and YouTube as well. In her interactions on these platforms, she only had a primary account that she used.

Adina shared her Facebook and Instagram data. She had Facebook data for the full 18 months prior to her initial recovery. However, she started her Instagram account four months prior to the initial recovery. During this period of time, Adina posted 576 posts or pieces of content. Adina's network seemed to be not entirely engaged in her content: her posts were not heavily favorited/liked (average 8.62, range 0-43) nor was there active engagement as measured by comments on posts (average 2.26, SD=3.19). Table 7-3

highlights the specifics of her data. The frequency of Adina's posting follows a specific pattern: her activity continued to increase until two months prior to the initial recovery turning point: in those two months there was a precipitous decline in her online posts. Figure 7-4 depicts this pattern of post frequency.

Table 7-3. Characteristics of Social Media Activity: Adina

<u>Breakdown of Posts</u>		<u>Type of Posts</u>	
Facebook	1142	Text only	0
Instagram	86	Text + Image	127
		Image Only	1063
<u>Post metadata</u>		Relationship Status	1
Avg. likes/post	65.4	Links	9
Avg. comments/post	2.1	Videos	17
% posts w/hashtags	7.9		

The LIWC analysis of Adina's social media posts indicated that the content showed more positive than negative affect (12.7 vs 2.7, respectively) with her positive affect actually increasing slightly throughout the duration of the time period assessed (Months 1-5, 12.5.; Months 6-12, 12.5; Months 13-18, 12.7). She talked very infrequently about her body (0.9) and her health (0.7). A majority of her posts focused on the present (6.0) vs looking back to the past (1.4) or to the future (0.7). The LIWC assessment also showed very little content associated with personal insight (1.0). The insight category showed a stark decline over the duration of the analysis period (Months 1-5, 6.3; Months 6-12, 1.3; Months 13-18, 0.9) as depicted in Figure 7-5.

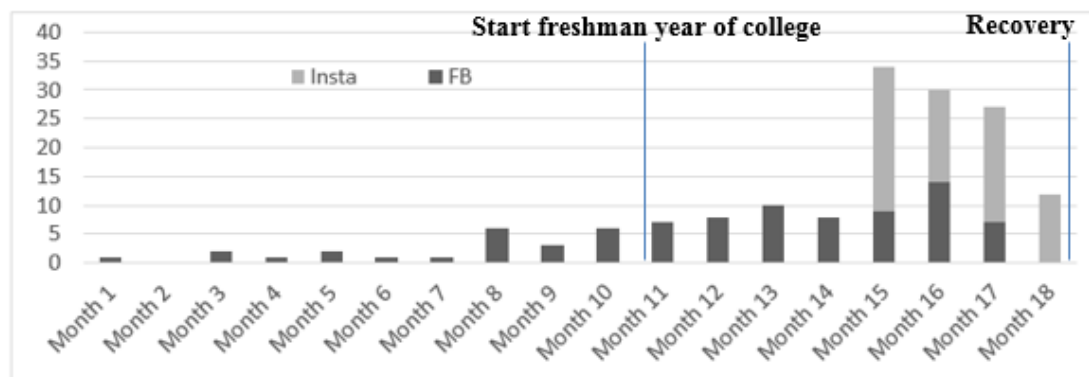


Figure 7-4. Social Media Data Over Time – Adina

The qualitative assessment using the codebook resulted in a more nuanced and holistic understanding of her perceived identity. For example, Adina's text was highly varied - the text attached to the social media posts covered every category except physical health and mental health. Of the posts that had text associated with them, 13.7% were labeled emotionally positive, 33.8% were neutral, and 8.1% were celebratory. Over 1/3 of the posts (35.6%) had emojis embedded in the post text. The point-of-view (POV) measured as either internal, external, or both, resulted in a particularly interesting result. Figure 7-5 highlights that Adina's posts reflect stable patterns related to the point-of-view associated with the text - meaning was it internally or externally focused or both. It was not until the last six months leading up to the start of recovery where the strictly internal and external posts began to decrease and more complex posts that contained both points of view were assessed.

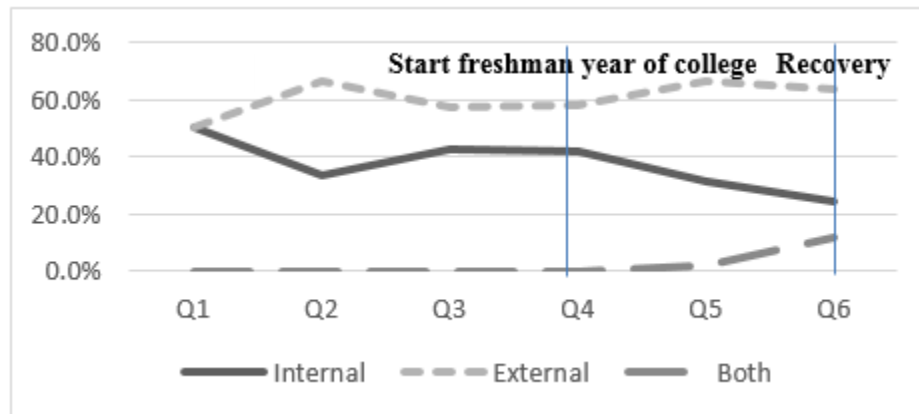


Figure 7-5. Point of View of Posts over Time – Adina

The media shared on Adina's accounts rarely featured herself - her likeness was identifiable in only 32.3% of the media. Where she is visible, the most common aspects are her face (85.0%) and her torso (37.5%). This is to be expected as they are common poses for pictures, but oddly there are few images that capture the lower half of her body. Almost equal amounts of media focused on family (27.8%) and friends (25.94%). The media found in her social streams reflected the typical media of teenager: images of friends, family, vacations/trips, and everyday life as depicted through studying, chores, and work.

Technology Use in Relation to their Eating Disorder. Adina never intentionally looked for websites that would help or make her eating disorder worse. She was unaware of these websites until she was in recovery. Her use of social media and the Internet focused on calories - how to reduce caloric intake or how to substitute ingredients for lower calorie replacements. To track her calories, she began using MyFitnessPal. Anytime she consumed calories or exercised she used this tool.

She does not remember using specific pro-ED terminology in her web or social media searches. She did search for things like “low calorie,” “no calorie,” and “negative calorie.”

Additionally, she would research exercises that burned the most calories. She did not engage in weightlifting because she viewed that as gaining weight even though she knew it was gaining muscle.

One of the most problematic aspects of the technology she used was the “People you Should Know” tab on the Instagram platform. Adina's social media feeds were filled with diet and fitness posts. She would find hashtags through those, just clicking through them and then you are suddenly “somewhere else.” An issue on Instagram as well as Facebook is the culture of sharing curated, often modified images that depict unrealistic and unattainable standards. She kept coming back to the point that all of these platforms can be used for healthy endeavors, but they are problematic for people with eating disorders or exhibit eating disorder-related behaviors.

Adina's social media data reflected only one of the media archetypes associated with previous eating disorder research - 8.02% of the posts were coded as related to diet. While these posts might technically fit this category, we have assessed them to be common posts associated with food. Figure 7-6 highlights several exemplar posts of this data. Adina also shared inspirational content (7.5%). These included inspirational text, inspirational quotes, and media that incorporated inspirational text with images. Figure 7-6 depicts exemplars of this content.

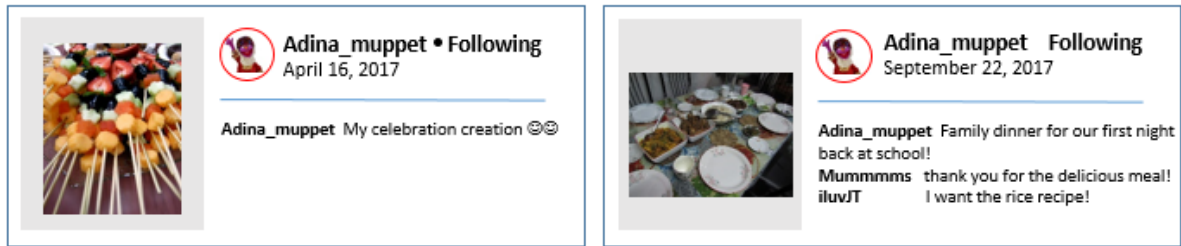


Figure 7-6. Example of Diet Media Archetype – Adina

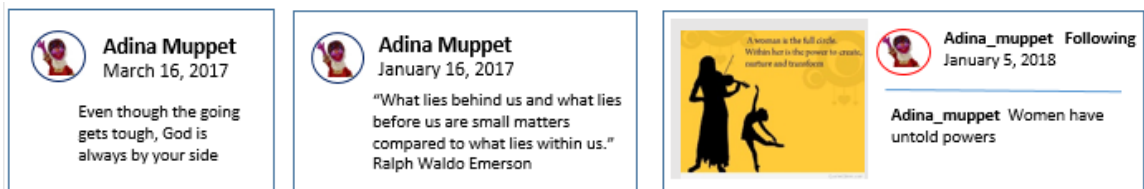


Figure 7-7. Examples of Inspirational Content – Adina

None of the identified ED terminology from this previous research were found in the lexical analysis of the posts. This observation, combined with the lack of media archetypes and the LIWC analysis results, indicate that our current methods for finding and assessing online eating disordered content would not have identified Adina as being at risk, despite that she was clearly at risk during this time period as deduced through the review of her medical records and validated through her interview data.

Technology's Perceived Impact on their Eating Disorder. The use of platforms like MyFitnessPal had a significant impact on her health. It was when she found MyFitnessPal that her eating disorder got much worse. She recounts the impact of seeing the graphical feedback on her daily deficits. Having a visual representation of her data - how many calories she had eaten and the lack of exercise to cancel those calories out - caused her to develop an unhealthy relationship with exercise, specifically running.

With respect to her eating disorder, she reported that she had used social media platforms to access extreme weight loss or eating disorder-related content and had posted content related to her eating disorder. However, the posting of ED-related content came with a disclaimer: she recalls disguising her “love for exercise” on Instagram to look up content that fueled her eating disorder. She remembers being heavily influenced by the content she would seek/engage,

“When I was actively engaged, I would feel triggered...I would also experience anxiety for not being like the picture or post that I was viewing. While I do not currently seek out this [content], I do run across them in my Instagram feed. They don't affect my behavior but can negatively impact how I view myself. I will delete Instagram if I feel like this is impacting my day-to-day life.”

Support organizations played a critical role in Adina's recovery. She discussed at length about her interactions with a non-profit organization that gives financial support for ED-focused treatments. They also have an active social media presence, posting inspirational quotes and people sharing their own recovery journeys. This support made her feel less alone. In a time when she often felt like she was never going to be normal, never be able to eat normal or be the same person again, seeing exemplars of those that found success in their recovery was very encouraging. Adina also had a robust peer support group. Her roommates knew the power of inspirational quotes for Adina in her recovery and would send them to her daily. It reminded her that there were good things in the world.

7.4 The Role of Social Media Platforms.

During the interviews, we asked the participants what responsibility they thought the social media platforms should have in relation to moderating pro-ED style content. Two of the participants (Margarita and Adina) were very vocal that platforms should intervene not only when people are posting content, but also when people try to search for said content. Margarita thinks that when you flag this type of behavior it shouldn't just be a community violation but should trigger the platform into action so that person can get help. She thinks they should be stricter as it relates to pro-ED content, especially about some of the things she used to see on the platforms. *"I mean, Pinterest even has them, it's everywhere."* Adina agrees, and believes that if the platform would have intervened, it would have made somewhat of a difference, especially in the time when she "had no clue" she was actively battling an eating disorder. She shared,

"It might have said something to me, like hey something seems a little bit wrong. You know, even if I didn't take it seriously, it [would still be] there somewhere in the subconscious"

Sheila was a bit more cautious, but still thinks that platforms should intervene, offering,

"Ideally it would be nice, but it seems like it would be difficult. I feel like people that want to get around it will get around it somehow, but that doesn't mean that nothing should be done. Basically, yes."

7.5 Implications

These case studies present vivid examples of online content helping foster dangerous norms, providing justification for the reasonableness of disordered practices. The patients in our study essentially discussed “self-triggering” - seeking out content to sustain and justify harmful behaviors and negative self-images. The idea of self-triggering fits within the concept of and expands the boundaries of the digital self-harm definition put forth to the community and described in Chapter 3 [200]. All participants in this study described the use of technology as an accelerant to their diseased thinking, that immersing themselves in pro-ED social media content cultivated a deeper sense of support and “normalcy” for their diseased behaviors. These behaviors support the theoretical underpinning of the expanded definition which focuses on using Social Cognitive Theory (SCT) and Cultivation Theory (CT) as an explanatory mechanism. A key tenant of CT is that the [technology] shapes the way individuals within society think and relate to each other [91]. The aggregation of pro-ED content that is indexed, easily accessible, and always evolving with new content creates an environment conducive to attracting people into the community and keeping them engaged. It gives the isolated individual a way to relate to others struggling with the same diseased thoughts and perceptions.

The use of other technologies in addition to these online spaces profoundly impacted the overall impact of technology in relation to the participant’s perception of their disease. The frequent use of fitness and diet apps to track and accelerate disordered behavior validates findings from Eikey and Reddy that this activity is dangerous and cyclical for patients [69]. The instantaneous feedback that the wearable technology provides in addition to the visualizations of the data tracking overtime that platform like MyFitnessPal provide their users can also establish an instantaneous and, if used improperly, dangerous

justification for a patient to engage in diseased-related behaviors. The connections between how patients use multiple social technologies simultaneously to foster and amplify disordered behaviors is both concerning and underplayed within the HCI and mental health literature. Understanding how the technical affordances of different technology interplay and the impacts of these interactions is vital as we continue to see more platform integrations within the social technology domain.

Within the CSCW and HCI community, we have diverse sets of methods that can be used to characterize, define, and explore our relationship with technology and the impact of this relationship on our everyday life. The community has used computational methods for identification [20,45,204,214] and prediction [39,50] of mental illnesses, including eating disorders. While this research has yielded valuable insights into these phenomena, the methodological approach is limited with regards to facilitating a holistic understanding of the individuals creating these data. These tools only work if the patient or person struggling with a mental illness uses certain linguistic choices or patterns or shares specific types of media. In our assessment, we found that our patients' social media data did not display the typical pro-ED content known to our field. Therefore, if we were to use the current standard of social media assessment tools on this data, we would find these patients to be not at risk, while we clearly know they were high-risk based on their interviews. The tools used by our community for the detection, prediction, and characterization of these mental health disorders are not yet sensitive or sophisticated enough to detect accounts of individuals that are not activated to a point of public disclosure or those that are very careful about the perceptions of their online identity. For this analysis, these approaches did not pick up on the types of interpersonal shifts within the complexities of the patients' lived

experiences. This work is critical to our field's understanding of how mental illness is presented within online social spaces and how our advances in sophisticated algorithm development could be applied to identify individuals in need earlier in the disease state, potentially intervening earlier in the disease progression which supports what is known clinically about early intervention with eating disorder patients - when identified early, therapeutic treatments are more impactful [246], serious psychological and health consequences can be prevented [81], and certain types of eating orders can be potentially prevented [236].

7.6 Design Considerations

7.6.1.1 Social Computing Technologies

With respect to the use of social technologies, we asked each patient about their thoughts regarding the role of the technology operators and if they should be responsible for moderating this type of content in their digital spaces. They all agreed that operators should intervene, ultimately creating and maintaining safer spaces for users to inhabit. Our patients point to multiple variations of "falling into" more troublesome content by following the algorithmic-derived suggested content and accounts in addition to search results. Platforms such as Tumblr have begun to address some of these issues through the use of lightweight interventions when searching on specific disordered terminology like "pro-ana." Before viewing the results of the search, the user is confronted with a screen asking them if "everything is okay" and then pointing to support services. This model could be used by other platforms, providing points of reflection for users before the self-triggering activity is completed.

This leads to the first design recommendation: **online platforms should include an intervention when certain terms are used for search.** Ongoing CSCW and HCI work has focused on understanding the lexical patterns and shifts associated with the eating disorder community that could be used within this function for social media platforms [40,193,195], but that is not the only access point online to this type of content. Additionally, this function should not be focused on just individuals searching for content, but also for those creating content. This leads to the second design recommendation: **online platforms should include an intervention when certain terms are used in the creation of a post before the post is uploaded to the platform.** Platforms should innovate how they moderate this content. Instead of not allowing an individual to post because a certain term is used, they should also include the same type of intervention for those seeking pro-ED content on their platforms. The psychological nature of platform interventions could vary as platform designers could look at a host of psychological and behavioral constructs.

Cognitive Behavioral Therapy (CBT) could be potentially well suited for this type of intervention as it is a short-term therapy with a primary objective to help the user understand the connection between their feelings, thoughts, and actions [152] and has been shown to be a more effective treatment of eating disorders than medications and interpersonal therapies alone [172]. CBT has found to be beneficial in mobile applications focused on addressing a variety of mental health conditions like Major Depressive Disorder [126], PTSD [134], and anxiety [213], but a majority of the apps available lack scientific evidence about their efficacy [64]. The challenge for future research will be how to translate the positive design aspects and outcomes from these mobile tools - as well as other

examples of therapeutic treatments being delivered remotely - into asynchronous and brief encounters like those that inspired the first two design recommendations.

Social media platforms served a dual purpose in the lives of our patients: they were vehicles of digital self-harm, but also tools used for support and recovery. Although these case studies focused on retrospective accounts and analysis of digital self-harm and the patients' corresponding eating disordered behaviors, we did glean some insights into the role of social media and technology for the recovery process. Notably, all of our patients relied on online sources of support and inspiration for their recovery process. This leads to the third design recommendation: **interventions designed to help people searching or creating pro-ED content should not only point individuals to standard help resources but should also encourage individuals to engage with pro-recovery communities within the platform.** In contrast to other damaging health behaviors, such as smoking, the advice to those aiming to change their behavior cannot be advised to avoid locales and social situations where those behaviors are commonplace. Even the disturbing persistence of social media to promote content based on historical actions and networks renders making a clean break especially challenging.

7.6.1.2 Clinical Practice

From a clinical perspective, it is troublesome that clinical assessments and treatments did not touch on the role of technology and exposure to harmful content in any of our case studies, even when it was directly indicated by the patient. The interviews in this study indicate that digital self-harm has a potentially more profound impact on the patient's disease state than we understand. Currently, there is not a consistent or validated approach

to assessing the role and impact of technology within the clinical context, let alone a path for addressing it during treatment and recovery. Clinicians have screeners that assess a variety of influences on behavioral health including drug and alcohol use tools, adverse childhood experiences assessments, and trauma [220]. There is currently not a standard screener or tool that assesses a patient's technology use and potential negative behaviors associated with it. Previous HCI studies have pointed out this need, as the access and complexity of the technologies continue to increase, especially within youth populations [192]. This leads to the fourth design recommendation: **social computing researchers and clinicians should partner to develop a tool that would elicit information from patients about the use of technology in conjunction with their diseased behaviors**. Such a tool would give clinicians powerful insight into how their patient's individual technology use impacts their disease presentation, allowing the clinician to address that specific influence on their patient's mental health.

7.7 Methodological Limitations

While I actively recruited patients of all gender and cultural representation, the participants in this study all identified as female and White/Caucasian. Based on 2018 Census data, the Fort Wayne/NE Indiana population is 74.2% White/Caucasian, 15.0% Black/African American and 8.7% Hispanic/Latino which further complicates recruiting an ethnically diverse population [251]. Because of the nature of the study design, there is a limited number of experiences illustrated - our participants presented with more traditional examples ED symptomatology like bingeing, purging, restricting, and excessive exercise. Similar to other case studies, the goal of this work is to gain deeper insights into a specific phenomenon. In this work my aim is to connect knowledge bases built on public data with

the lived experience of patients to assess if patients would embody these documented behavioral patterns. Future work could validate or expand upon our findings with larger, more inclusive and representative populations. Additionally, our IRB required that recruitment be limited to patients who were determined to be stable in their recovery by their referring physician. The constraints on the inclusion criteria limited the participant pool for this study.

Scalability is another limitation to this approach - it would be near impossible to replicate this approach with 100,000 unique social media users (the user pool size of a recent eating disorder-focused qualitative study [39]). These data-driven approaches illuminate aspects of this research space that are critical but also have the potential to replicate implicit biases, specifically within the mental health space [193]. Encouraging a diverse community of research can help address these tensions, utilizing the strengths of the different methodologies to create a stronger, more complete knowledge base.

7.8 Ethical Considerations

It was important the participants felt safe as they discussed their mental illness. A clinical nurse or mental health professional was present during all of the patient interviews. Myself and anyone else who was present in the interviews also went through QPR training, a program that teaches an individual how to recognize when people are in the beginning stages of crisis and how to react in that situation [210] and ASIST training which provides people with professional development to ensure they are prepared to provide suicide first aid help as part of the care they might provide [145]. Additionally, I created a resource list of local, state, and national supports and resources for participants to take with them at the

end of the interview in the event that talking about their past mental health issues had a delayed negative impact.

To ensure that the identities of my patients were not comprised, all personal identifiers (names, social media posts) were created as representative exemplars of the actual content. Certain aspects of the patient's individual narratives have also been slightly modified as to maintain their anonymity.

7.9 Conclusion

Moving forward, it is imperative for the HCI and social computing communities to critically reflect on our current understanding of the relationship between an individual's mental health and how we frame our understanding of it through their online activities. While small in number, our case studies highlight how individuals self-describe the impacts of their digital self-harm activities, all the while their social media data does not indicate a mental illness. Prediction and detection are simply pieces of this complex and ever-changing puzzle. Deeper knowledge of the human within the human-computer interaction is needed if we are to strive for a more holistic and diverse understanding of digital self-harm and its impacts on our everyday lives. This understanding is pivotal in the translation of this knowledge into clinical practice, potentially through the development of assessments and treatments that factor digital activities into a richer understanding of mental illness and the activities that support them.

CHAPTER 8. DISCUSSION

8.1 Ethical considerations

In addition to the focus of this body of work, key ethical tensions and issues were also something that I engaged with on a regular basis. In this section I will discuss the various ethical challenges, concerns, and decisions I made along the way in carrying out this body of research.

In the initial studies that focused on characterizing eating disorder content online, a key factor for myself and my collaborators focused on defining our own group membership, identities, and potential lack of knowledge about this group's – people discussing eating disorder behavior and activity - lived experiences. It was important to me that we have open discussions about these deficiencies and make sure that as we disseminated the research, that we explicitly noted this deficiency [198]. While it is not always possible, having researchers who have deeper knowledge of these communities or are a part of these communities can help navigate misinterpretations and highlight various sensitivities needed to ensure respect and appropriate methods and analyses are used within the research.

A common theme across my research and most other social computing scholars researching mental health aspects on social media is the use of public data. Public data is defined as “information that can be freely used, reused and redistributed by anyone with no existing local, national or international legal restrictions on access or usage” [243]. Many social networks have user sign off to a worldwide, non-exclusive, royalty-free

license to use which authorizes the platform to make the user's content available to the rest of the world and to let others do the same [282,283]. Thus, I collected data without knowledge or consent of the users who created the content. While this practice is common in HCI, there are assumptions implied that might be problematic. The main assumption here is that people that have signed a TOS to join a social media platform and uploading content *understand* or have the *technical literacy* to fully comprehend the ramifications of this choice.

To test this theory, I devised a procedure during the initial characterization study where I reached out to the account owners of all of the media that was used in the publication and that would be presented at the conference where this research was published. I reached out to the 17 accounts from which the images were taken. In the message, I made sure they knew that I was a PhD student from a public university that had come across their post in a general platform search. I gave them a two-week period to request that their materials not be used in the publication. Only three people responded to this message. They all commented that they did not care if I used their content and two further stated that they found it "odd" and "strange" that we would care about their content. While this process was plausible since I was conducting a qualitative study and therefore didn't have to reach out to that many individuals, it raises an interesting question of if a process like this should be taken regardless of how many people would have to be notified. Through this process, we gave individuals the ability to opt-out. During the research outlined in this dissertation, the European Union passed a directive called the General Data Protection Regulation (GDPR). In these sweeping provisions, the GDPR included that it is not enough to simply opt out, but that processes have to be put into place that require you to *opt in* and agree to

your personal data being shared or reused [249]. As these types of policies are enacted beyond the EU, the type of research carried out in this dissertation and the responsibilities on the researchers conducting the studies will definitely change to be in compliance with these new policies.

Additionally, as this research continued, so did the computational capabilities of online search tools. Introduced in 2011, the Google reverse image search capability changed how people search for images online. This feature allows a person to drag and drop an image into the search bar and will scrape the web for pages/spaces that contain that image or images that are similar [129]. This capability presents an issue for researchers utilizing online media in their analyses. There is a growing consensus amongst HCI researchers focused on mental health domains that content – including media and text – should be de-identified or paraphrased in order to conceal the identities of the public accounts from where the data originates [5,105]. In the characterization study discussed in Section 5.2, all images and text from the posts that were presented were heavily modified and tested in a reverse Google search test or paraphrased. If a piece of media could not be manipulated, I found similar images from popular news or magazine articles to serve as a proxy for the original media. In the research discussed in Chapter 7, all personal identifiers (names, social media posts) were omitted – I created representative exemplars of the actual content. Additionally, I modified certain aspects of the patient’s individual narratives to maintain their anonymity.

Another key assumption in this vein of research is that social networks and platforms do not have the obligation to intervene. This topic of content moderation, regulation, and should national governments have oversight into these platforms is beyond the scope of

the research presented here. However, many platforms have begun the process of not only moderating eating disorder content, but also providing light-weight interventions for people who are conducting searches associated with eating disorder content [41]. Through this research, patients agreed that interventions within these online platforms would be beneficial and that current interventions are not doing enough to divert individuals from searching for harmful content within the platform. The findings highlight how important it is to approach these interventions with a delicate, purposeful, and clinically grounded context in mind in order to keep the intervention from becoming counterproductive or possibly a form of manipulation in itself [41].

However, platform interventions are not an unambiguously good idea. While platform interventions might be helpful, that is still unknown. While there are definite potential benefits as enumerated above, there are also potential negative consequences as well. More research is needed to understand the complex privacy issues, the long-term impacts of these interventions (both positive and negative), and how receiving an intervention changes your relationship or orientation towards social platforms.

During the research discussed in Chapter 7, it was paramount to ensure that my subjects were treated in the most respectful and ethical manner possible. Obtaining access to a population of patients with a clinically defined eating disorder and the processes put into place to ensure this aim were extensive. When working with sensitive populations like this group, and asking them to entrust you with years of their social media data, additional steps were taken that I believe are important to share and believe should become standard operating procedure within our community. First, there was no direct recruitment for this study. Not only did the referring clinical provider review their case and believed that they

were stable in their recovery, but a clinical psychologist working in partnership with this research also reviewed their records to make sure that they were stable in their recovery, thus mitigating the potential adverse negative impacts on the subject participating in the research study. Additionally, the inclusion criteria defined “stable” as not having had a suicidal ideation or attempt in the past 12 months and not had more than 2 relapses in the past 6 months. Relapses were defined as a binge, purge, restriction, abuse of a diuretic, or any other type of activity associated with specific eating disordered activities. Upon reflection within the research team, my clinical partners agree that this was probably too stringent, that patients could have had additional relapses but still be considered stable enough to participate in this research.

In preparation for engaging patients in the interview study, myself and anyone else engaging the patients (e.g. project manager) were required to obtain QPR and ASIST certifications. QPR training is a program that teaches an individual how to recognize when people are in the beginning stages of crisis and how to react in that situation [210]. ASIST training provides individuals with professional development to ensure they are prepared to provide suicide first aid help or intervene as part of the care they might provide [145]. Additionally, I created a resource list for participants to take with them at the end of the interview in the event that talking about their past mental health issue had a delayed negative impact to their emotional state. During the interviews, the research design called for additional procedures to take place. A clinical nurse or mental health professional was present during all of the patient interviews. The healthcare provider was directed to monitor the responsiveness of the participant and interject with a specific question if they felt the participant was becoming uncomfortable or noticeably impacted by the discussion taking

place during the interview. We explained why the additional person was present for the interviews and made sure that the participant was comfortable with their presence.

The final extra compliance component of this research study included an extended review of the informed consent process, especially when it came to the collection and review of their social media data. Participants were verbally walked through, in-depth, the procedures that would take place and how their data would be handled. Participants were consented at the end of the interview so that they did not feel pressured to participate in both the interview study and the social media analysis study. Two of the participants had clarifying questions related to the data analysis and how the data was going to be obtained. Through staggering the consenting process and walking through the data analysis process in a very detailed manner, it is my intention that the participants did not feel coerced to participate in the social media study and that they were well informed when they made their decision.

8.2 The role of online tools as a facilitator of eating disordered behavior

Social media is a continually evolving ecosystem – as I have seen through the duration of this research, the technical affordances of platforms change as the technology advances and policies that govern platforms internally as well as the policies of the location where the users live impact these online communities. As I have outlined in Chapter 2, there has been an evolution of how people use the social web in relation to their eating disorders as the social web itself has grown and matured. In this dissertation, I have defined the concept of digital self-harm, where the actual use of the online tools is a component of the diseased behavior/self-harm.

In Chapter 7, all of the patient participants discussed the role that MyFitnessPal played in their eating disorder trajectory. They shared how quickly they moved from using it as a tool to chart their food intake and exercise each day to an obsessive process, where the tool was utilized in excess of 15 or 20 times a day and governing how the patients lived their lives. The dietician we worked with in this part of the research validated that this platform and others like it are often associated with devolving symptomatology and challenges that are more difficult to therapeutically resolve. The real-time data feedback and the platform ease-of-use contribute to the sustained use by patients and why the unhealthy use by patients can be so challenging to address.

Platforms that support this type of immediate data visualization of health status, that allow people to track individual calories eaten and burned through exercise are an obvious place for more directed, targeted interventions. The platforms have the ability to monitor uses that fall outside of “standard” or “normal” use. When an individual is opening the platform multiple times an hour, is this an indicator of problematic activity? When a 17-year-old female logs 500 daily calories consistently, is this an indicator of problematic activity? Currently platforms like MyFitnessPal, LoseIt, and Lifesum allow users to track food and exercise to an exacting level. These platforms currently have no systemic practices in place to address the utilization of their technologies to exacerbate negative health activities. A recent BBC investigation found content that promoted dangerous cycles of starving and bingeing in addition to other forms of self-loathing and hatred associated with eating disorder symptomatology [284].

The way these companies have chosen to intervene all vary. In response to the findings of the BBC investigation, MyFitnessPal deleted those entries that were highlighted in the

report, but it is unclear if other detection algorithms are in place. Unlike social media platforms like Instagram and Tumblr, the platform encourages users who log too few calories in a given time span are encouraged to review their dietary and exercise goals. LoseIt chose to close community groups that violated the community standards that explicitly give guidelines focused on healthy eating in the platform. Lifesum has provided nutritionists to users who might be concerned, choosing to focus on support than moderation.

While these interventions are a reasonable place to start – is it enough? What is the responsibility of platforms like LoseIt and MyFitnesspal to moderate how users implement their platforms? Choosing the more laborious task of supporting users over moderation addresses issues raised in my previous work focused on how social media policies potentially adversely impact people with eating disorders who are moderated for sharing aspects of their mental health state with the community [191]. Yet it leads into another concern – technology companies assuming the role of informal healthcare facilitators. What aspects of MyFitnessPal or Instagram make them qualified to serve in this role? It is safe to assume that when users sign up for these platforms, they do not *expect* the platforms to serve in this role. It is not understood what if there is misalignment between the platform and the user in this regard. If platforms are continuing to move in the direction of fulfilling this informal healthcare facilitation role, research is needed to understand the impacts of these misalignments and inevitable interventions executed by these platforms.

This research is just the start. As computing technologies become even more sophisticated with the integration of AI, digital phenotyping, and AR/VR experiences and users generate even more data that is becoming more interconnected, the ways and means

for using technology as a facilitator for negative health and wellbeing will exponentially expand. Thus, it is imperative that while the HCI field continues to explore the ways that technology positively impacts our lives and provides us various vehicles to enhance our lived experience, we also need continue to develop our knowledge base with respect to how the technology negatively impacts our everyday lives. As these aspects are uncovered, it is imperative that the HCI community works across disciplinary lines to ensure that people developing the technology, those enacting policy, and the individuals upstream dealing with the impacts are part of the solutions that arise to meet the challenges of these technologies being used as tools for harm.

8.3 Implications for Social Computing Platforms

There are various aspects of this dissertation research that raises questions associated with the current standard practice of assessing mental health states via social media. The case studies presented in Chapter 7 highlight the invisibility of these patients within the social media platforms. None of the patients reported creating specific pro-ED. An analysis of 18 months of their social media content supported their self-reports. Utilizing the standard methods of detection only result in those that are willing to broadcast aspects of their disease to the larger community within the platform or, in terms of Goffman, act out these behaviors on a public stage. A deeper analysis of the patient's social media posts illuminated patterns that might be useful in identifying that a mental shift has taken place, but without the context of talking with those patients I would not have been able to identify that there was an issue with eating disorders taking place in the lives of those individuals. Additional technology use, like MyFitnessPal, even further complicates the issue of

invisible impacts. The patients I interviewed discussed the immense amplification of harm when they combined these technologies.

So what does this mean for social computing research that is focused on detection of mental health states? The tools used by our community for the detection, prediction, and characterization of mental health disorders are not yet sensitive or sophisticated enough to detect accounts of individuals that are not activated to a point of public disclosure or those that are very careful about the perceptions of their online identity. That is not to say that the current methodologies are important and need to be further explored. If platform-based interventions and potential clinical interventions are based on this paradigm, the risk for creating healthcare disparities is a real risk. A potential way to ameliorate this risk is potentially stronger connections to the health system. If the knowledge base of digital self-harm activities includes not only online indicators but also data coming from provider-driven engagements with their patients, then there is a possibility that less disparity will be created and that the interventions rooted in this knowledge base will target a higher percent of the population struggling with these issues.

8.4 Implications for Healthcare Systems

As the field of healthcare continues to focus more on social determinants of health, and more specifically how social environments shape mental health and many common mental disorders, the online environment and people's interactions within them will become increasingly more salient within the contexts of traditional healthcare [265]. If information about a patient's technology use is to be collected, standards in care for mental health must be changed. In Chapter 6, the healthcare providers indicated that technology use is not part

of their assessment processes, yet several indicated that it probably should be part of that process. Creating specific technology use patient questionnaires sounds promising, but the reality of clinical constraints and the willingness for providers to add yet an additional formal component to assessment makes this approach less than ideal. An attainable process might include providing education to healthcare providers about common uses, abuses, and patterns of concern

Beyond collecting information about how patients use technology is the subjective review of actual online behaviors. If social media data is to be included into this ecosystem, a more inclusive understanding of how mental illness presents within online social spaces is essential. With a deeper understanding, advances in sophisticated algorithms could be applied to identify individuals in need earlier in the disease state, potentially intervening earlier in the disease progression which supports what is known clinically about early intervention with eating disorder patients — when identified early, therapeutic treatments are more impactful [246], serious psychological health consequences can be prevented [81], and certain types of eating disorders can be potentially prevented [236]. Part of the deeper understanding is accessing the background data that is not currently public – this type of data includes search history, time spent viewing content, and the click-through behaviors of embedded hyperlinks and attached hashtags. As indicated in Chapter 7, these types of behaviors (or changes in behavior) could signal changes in behavior as it is taking place instead of after-the-fact.

A concern amongst the providers focused on potential issues of integrating this type of data into the electronic health record (EHR). In Chapter 6, the interviews with the clinical providers highlighted the tension between being able to potentially identify patients earlier

in their disease trajectory (which has proven to have better long-term benefits for some mental illnesses [87]) versus the appropriateness of using this non-clinical data and potential ethical and social issues that could evolve when you connect health and social media data. Even if you need reason to look at psychiatric records – or needing to break the glass – there is still the possibility of that data propagating into systems where the user never intended it to belong. There is also the issue of social media data and the authenticity of it as it relates to the individual. Earlier in this chapter, I discussed the appropriateness of social media platforms becoming unofficial healthcare facilitators. This begs the inverse of this discussion – are health systems equipped to process and understand vast amounts of social media data?

8.5 Replicating This Research

As HCI and Computer Science continues to expand and build stronger connections into the healthcare domain, researchers will need to continue to establish deep connections with their partners in healthcare. A unique aspect to this partnership was that it was not just advisory in nature; Parkview invested in this research by integrating me into their system. I was not only invited to talk to providers and patients, but I was integrated into workflows. This level of integration strengthened the research because I was seen as *part of the system* and not just someone working *with the system*. This is a key differentiator as I was seen as a trusted member of the Parkview family which afforded me more favorable status than if I was just an outsider partnering with the system. As with most relationships, this process took time and good faith to establish and nurture.

As with any research endeavors there were several breakdowns that threatened the continuation of the research. The largest issue was the IRB. The IRB was submitted with Parkview as the lead agency. As a community hospital-based IRB, Parkview did not often review HCI-based research protocols and had never reviewed one with social computing aspects. This protocol took eight months and three full-board presentations before it was approved. Each presentation and the feedback that was generated from it contributed aspects that strengthened the ultimate research design.

A key outcome from working with the IRB was not only having a clinician consulting on the research protocol, but having a clinician as a full contributing member of the research team. For Parkview, they were not satisfied that we were working with clinicians, engaging them on various aspects of the research. They wanted to be assured that the clinician was with the team at every aspect of the research design and meaningfully contributing to the research. Thus, we recruited a clinical team member to be a Co-PI in this research. We were already working with Dr. Brown, strategically utilizing her during specific aspects of the research design. By having her advisory board approve her collaboration, it gave her more time to contribute but also provided more formal support for the research within the health system.

I would encourage social computing and HCI researchers in the healthcare space to choose the more challenging, longer path of creating meaningful collaborations with health systems or clinical providers for their research. Having this expertise in an advisory capacity is a great start, but there are a multitude of hidden assumptions on both sides that leads to outcomes that are not fully representative for the computing field (as witnessed with the bias in my original research) and not actionable for the healthcare system or

provider. The interdisciplinary and fully integrated approach taken in this dissertation research has resulted in several challenges to preconceived knowledge within both the HCI and Healthcare domains, thus shedding light on the need for deeper, more robust research to fully articulate the impacts of connecting the digital to the physical within the mental health domain.

CHAPTER 9. FUTURE DIRECTIONS

There are several research dimensions of this research that would be interesting to expand beyond the scope of this dissertation. I first discuss the policies and ethics related to using social media to identify an individual's mental health state and the incorporation of social media data into the clinical setting. I then discuss two possible design paths, one focused on embedded social media interventions, and one aimed at designing technologies that mitigate people from fixating on aspects of their health sensing that can actually have unintended consequences for users.

9.1 Policies and Ethics of Characterizing Mental Health Activities Online

A central tenant of this research is that pro-ED online content cannot only be a form of negative support for people with eating disorders but also a form of self-harm. Therefore, the characterization of eating disordered activities and behaviors are symptomatic of a medical condition. In addition to the research presented in this dissertation, I also conducted a study to understand how social media platforms characterize eating disorder behaviors [191]. I uncovered that policies across all popular social media platforms characterize eating disordered behaviors as self-harassment, akin to the initial concept of digital self-harm being a form of self-cyberbullying or online harassment of oneself. What is not understood is the impact on the diseased individual who was moderated or removed from an online community for activities considered as self-harassment. I envision that feedback from individuals that have gone through this process would be valuable to social media providers on how their policies, put in place to protect both individual users and the

community-at-large, is actually having adverse effects on vulnerable community members caught in this process.

For social media platforms, I encourage them to re-evaluate how pro-ED content is regulated within their communities. If platforms provide interventions for people that are searching for or *consuming* content, the assumption is the platform providers believe searching for this content is connected to a vulnerable mental health state that should be addressed. Yet my research shows that providers equate people that *produce* content as a form of harassment. I argue that content consumption *and* creation could be part of expressing digital self-harm, and thus should be handled in a similar fashion.

For researchers in this domain, I would share a warning about biases within the characterization of health states through social media content. In this body of research, I stumbled upon a serious gender bias within the research. My experience has taught me to not only question the data that I have collected, but also ask questions regarding what is missing. If I had asked that question earlier in the research, I would have seen this glaring omission. Within the research process, it is often difficult to protect the time to be reflective on what is present. It is as equally important to reflect on what is missing and investigate why there might be an absence of representation within the data as what is present in the constructed dataset. I would challenge the social computing community to not just talk about these biases, what we missed and what we would do differently next time, with each other informally, but formalize these discussions in research papers, workshops, and in our academic curriculum.

9.2 Integrating Social Computing Data into Clinical Practice

The wealth of social and emotional data that can be directly collected or inferred through social media activity provides an interesting and provocative question about how this data could be harnessed for clinical insights. As I mentioned in Chapter 6, healthcare providers shared trepidations regarding the formalized inclusion of this type of data into their practices. Currently, users' perceptions of privacy and what can be done with their online data are misaligned from reality: the example I provided in Section 8.1 highlights this as does other research focused on this aspect of user generated content [82] and privacy [144]. If social media data becomes a part of the formative (and ongoing) information that influences clinical care, this will affect how users orient themselves to these communities, how they engage with people and content within individual communities or across various different communities, and inevitably how they represent themselves within these spaces. If this shift in clinical practice were to take place, additional analysis would be critical to understand how these changes in norms and access to data transforms the relationship between user and platform as well as the user and their mental health provider.

9.3 The role of social media platforms as mental health interventionists

There are several social media platforms that have created lightweight interventions for those seeking pro-ED content. These interventions focus on creating an intermediary step between the search and the access to content. These usually convey that the search content indicates that the user might need access to health support mechanisms. It allows the user to choose between connecting with the health support or continuing onto the content. The patients in my research all indicated that they felt that, while this is a step in the right

direction, it does not do enough. These sentiments raise a critical question: should social media platforms be arbitrators of what is healthy and what is not? Is it their responsibility to create a behavioral intervention for people they believe to be suffering from a mental health issue? While these points will vary from platform to platform, there is one question that will remain consistent: are there negative implications, coercions, or manipulations that take place because of this in-platform intervention? Further complicating matters, there are regional, national, and supranational rules and regulations that impact the design and implementation of these potential interventions.

From a legal and a community perspective, understanding the platform's responsibility is paramount. As my previous research has depicted, users do not use singular social media platforms – they have a portfolio of platforms that are used in coordination with each other [199]. This portfolio is a living, evolving federation of tools used to connect to people, places, ideas, and support. Managing the various parts of this portfolio puts a high burden of digital literacy onto the user to understand and navigate how platforms mediate the expression of their disease. This raises additional questions of disproportionate disparities for those with the technical literacy to understand and navigate these nuances and those that are unable.

9.4 The use of technologies as a tool for tracking health and wellness

The design of health tracking technologies, be it a wearable technology like a FitBit or an online community to support data derived from health tracking technologies like MyFitnessPal, are a wonderful tool for many to promote healthier lifestyles. These tools also offer individuals who have an unhealthy orientation to the technology to fixate on

certain aspects of their disease like calorie counting and tracking fitness outputs. The simplistic design and data visualization of these tools do not take into consideration personalized aspects of an individual user's current health state. I envision a future for these tools that would allow users to inform the technology of certain issues – like depression or an eating disorder – and that the technology is responsive enough to change the way data is presented and consumed by this population. How would this type of personalization of health tracking tools impact the user's relationship to their health data and to the technology itself? By creating a more nuanced safeguard, can these tools be used as part of the recovery journey instead of being weaponized to further exacerbate a user's diseased state as evidenced through the patient interviews in Chapter 6 and with other prior research [68]? Future work is needed to understand how these technologies could integrate various computational approaches to achieve this vision and how modifying the presentation of data impacts patients using these tools.

9.5 Exploring Digital Self-harm

Beyond the pro-ED aspects of this research, it is easy to generalize these questions and research directions beyond eating disorders to other aspects of mental health like suicidal ideation, depression, anxiety, or even behavioral issues like substance abuse and sexting. Moving forward, I believe it is critical to move beyond characterizing the connections between the digital and the physical and begin exploring the correlational patterns and potential causal links between technology use and mental health symptomatology as a way to further unpack the concept of digital self-harm.

The online content that I assessed in the formative stages of this research relied solely on public data. This means that we do not know who created this content or why they created it. The patients I engaged did not create pro-ED content like that found in the formative research. Who is creating this content? What is their motivation? Does creating pro-ED content have a larger impact on an individual's digital self-harm than just consuming it? Moving forward, I believe this to be a key aspect of research that is needed to understand online networks of influence as well as various impacts on digital self-harm.

CHAPTER 10. CONCLUSION

My research focuses on defining how online activities and behaviors can lead to clinical manifestations of self-harm. I study these activities and behaviors through an extensive characterization of pro-ED content, posts and media shared online that represents aspects of the manifestations associated with general eating disorder symptomatology. I operationalize this research by combining HCI and social computing methodologies within the context of a traditional healthcare setting, connecting the research to clinical aspects of patients and mental healthcare providers. This research evaluates the hypothesis: *patients with a clinically diagnosed eating disorder who actively use social technologies will use social media platforms as a process of engaging with digital self-harm activities.*

First, I define an expanded concept of digital self-harm, connecting the medical constructs of self-harm behaviors to online activities that go beyond the cyberbullying of oneself. Second, I discuss the application of machine learning and linguistic analysis to computationally understand the pro-ED communities within various social media platforms. Third, I characterize the online presentations of the pro-ED community including biases within the computational understanding of the pro-ED community from the previous research activity. Fourth, I established a partnership with a healthcare system which allowed me to develop a set of studies to connect the findings from online pro-ED communities with a patient population. This allowed me to assess how digital self-harm activities are currently assessed by mental health professionals and how digital self-harm activities present within a patient population that is clinically diagnosed with an eating disorder. Finally, I examine the ethical implications, methods used, and impact my findings

have on the current state of computational detection and assessment of mental health states through social media activity.

Collectively, my research makes several contributions to the fields of social computing and health informatics.

Social Computing. For social computing, my research offers a comprehensive understanding of pro-ED activities and behaviors across social media platforms. Studies had previously looked at understanding online pro-ED activities and behaviors in traditional websites and blog, but I found little work focused on how this content manifested across social media platforms. Within this work I present a lexical dictionary of ED terminology and a set of media archetypes depicting the online activities as a whole – taking into consideration media and text uploaded to these online platforms. My research also identified how structural and policy changes within social media platforms impact the presentation of pro-ED content online. It highlights the lexical variation patterns associated with this online content as a way to develop workarounds technical and community-based moderation.

Additionally, I provide a number of design guidelines for social computing platforms with regards to platform-based interventions for people searching for pro-ED content within the platforms. These design guidelines are based on reflections from patients who used social media for digital self-harm activities that led to negative impacts on their health.

Health Informatics. For health informatics, my research connects patterns of online activity into the clinical context by using the results of the online characterization research to foreground an assessment of the presentation of digital self-harm with both patients and

providers. Previous studies within the health domain have characterized aspects of the behaviors outlined in my research, yet none have taken a holistic approach, looking not only at behaviors associated with traditional terminology but also behaviors associated with terminology not standard within the clinical context. By connecting patient's social media data with personal reflections on the impacts of technology on their disease, I was able to validate that patients engage in digital self-harm behaviors

Finally, my work provides a set of methods and ethical considerations for conducting research on mental health states in online communities. These contributions may be of value to both the social computing and health informatics communities as both communities are focusing on a variety of mental health conditions and technological influences. The methodological decisions and ethical considerations within this dissertation provide a model for future research studies looking to integrate social computing research into clinical settings.

APPENDIX A. PRO-ED LEXICAL DICTIONARY

Eating Disorders	adultswithed	anorexianervosa	eatingdisorder	menwithed
	ana	anorexic	eatingdisorders	mia
	anabuddy	anorexique	ED	orthorexia
	anacarefree	anorexix	edbuddy	proana
	anafighter	bigoexia	edcommunity	proanamia
	anafighters	bigorexia	edfamily	proanna
	anamia	binge	edfighter	proannna
	anasoldier	bingeeating	edfighters	proanorexia
	anatip	bingeeatingdisorder	ednos	proed
	anatips	binging	edproblems	promia
	anawarrior	bodycheck	edprobs	purge
	anawarriors	braziliananorexic	edrelapse	relapse
	anne	bulemia	EDs	secret_society
	annie	bulimia	edsoldier	secret_society123
	annorexia	bulimianervosa	edsoldiers	secretsociety
	annorexic	bulimiaprobs	edstory	secretysociety123
	annorexix	bulimic	edstruggles	vomit
	anorecia	bulimique	edwarrior	vomiting
	anorectic	bulimirexia	edwarriors	wannabeana
	anoressia	bulimix	manoreic	wannaberexia
	anorexia	bulmia	manorexia	
	anorexianerv	compulsiveeating	manorexiafoetus	
	anorexianerviosa	eatingbehaviour	manorexic	
Body	2pack	bubblegut	leanmuscle	stomach
	6pack	cheekbones	legs	thigh
	abs	chestbones	mesomorph	thighgap
	arm	collarbone	muscle	thighgapps
	arms	collarbones	muscles	thighgaps
	blade	flatbelly	pectorales	thygap
	blades	flatstomach	quads	thygapps
	body	foot	ribcage	tummy
	bones	hip	ribs	veins
	bouldersshoulders	hipbone	shadowabs	
	bubblebutt	hipbones	shoulders	
Drug	anabolic	gh	steroidmaximus	

	anabolics	idusesteroidsifihadit	steroids
	anabolicsteroids	lax	testosterone
	anadrol	laxative	
Identity	alphalete	gorgeous	powerlifter
	bane	grunge	pregnant
	bdd	gymsrat	pretty
	beautiful	gymshark	proud
	beefy	HealthAtEverySize	relatable
	biggerbytheday	healthymindhealthybody	ripped
	blithe	hipster	selfimage
	bodybuilder	homosexual	selfimageissues
	bodydismorphia	imfine	shredded
	bodydysmorphia	ironaddict	runaway
	bodydysmorphicdisorder	ironrebel	skinty
	bodydysmporpha	iwanttolookdisgusting	strongasfuck
	bodyimage	jacked	strongman
	bohemian	lifghtweightbaby	stupid
	boy	loser	swole
	buffdudes	malebodyimage	swoll
	confidence	me	tats
	cut	model	tattoo
	dadbod	muscledysmorphia	teen
	dysmorphia	muscledysmorphia	torquemonster
	emo	musclemadness	transformationtuesday
	enhancedathlete	musclemonster	trash
	failure	muscleoworship	ugly
	fairy	muscular	useless
	fanboy	muscultation	vintage
	fangirl	neverbigenough	weightlifters
	fine	notme	
	fitfam	pale	
	gainz	pathetic	
	gay	perfect	
	gaybodybuilder	perfection	
	gaymuscle	pig	

Depression	alone	emotional	nevergonnabehappy
	broken	empty	numb
	cry	failure	pain
	crying	friendless	painful
	dark	giveup	sad
	darkness	hate	sadness
	deb	heartbreak	selfhate
	depressed	helpme	tear
	depressing	hopeless	tears
	depressing	hurt	tired
	depression	igiveup	unhappy
	depression	ihatemyself	unloved
	depressive	iwanttodisappear	upset
	disappear	loneliness	worthless
	disgusting	lonely	
	down	lost	
Inspiration	belevetoachieve	iwanttogetmoremassive	progressnotperfection
	believetoachieve	jawlinespiration	promiathinspo
	bodyempowerment	keepfighting	slightprogress
	bodypositive	killmethinspo	thinpos
	bonespiration	legspo	thinspiration
	bonespo	loveyourbody	thinspire
	bonespoo	malebodyposi	thinspo
	comments	malethinspo	thinspo
	fatspo	motivation	thinspoo
	fitspiration	motivations	thinspooo
	fitspo	mythinspo	thynspo
	gethenchordieskinny	naturalthinspo	thynspoo
	gympso	neversatisfied	whateverittakes
	icantdie	nevertobig	yourebeautiful
	inspiration	positivebodyimage	
Recovery	HealthNotDiets	positivity	success
	life	progress	trigger
	love	prorecovery	triggerwarning
	mediation	recover	tw
	nourishnotpunish	recovery	warrior
	positive	strongnotskinny	

Fitness	10/5k	fitness4freakz	powerlifting
	2adays	fitnesslife	powerlifting
	bars	fitnotthin	pump
	bloodsweatgains	gains	run
	bodybuilderproblems	gto	runners
	bodybuilding	gym	running
	bodybuilding	gymaddiction	sandbagtraining
	bodypositivityweek	gymlife	squat
	bulking	howmuchyabench	squats
	calisthenics	instafit	streetworkout
	cardio	instafitness	traininghard
	chestday	instarunners	trainnaturally
	crunch	itsagymthing	weightlifting
	cutting	legday	weights
	deadlift	legextensions	weighttraining
	detroitpowerlifting	legpump	workout
	exercise	massthetics	worldgym
	fit4life	menshealth	
	fitfam	monstersdoexist	
	fitness	neverstoprunning	
Food	abcdiet	fast	notfood
	anadiet	fasting	nutrition
	anafood	food	plantbasedprotein
	breakfast	foodie	restrict
	calories	foodisfuel	skinnygirldiet
	cheesecake	haggus	starvation
	cleaneating	healthyeating	starve
	diet	healthyeats	starving
	dietcoke	healthyrecipe	sugarfree
	diets	healthysnacks	vegan
	donteat	highcarb	veganrecovery
	eat	ketogenicdiet	whatsyourprotein
	eat4abs	lowcal	yummy
	eatclean	mono	zerosugar
	eatforabs	monodiet	
	edfood	myfood	

Social Support	bodygoals bodyshamming breathe bulied bullying challenged competition	dontgiveup followforfollowback Icare itgetsbetter like4like neverquit peersupport	rantstaystrong reachout staysafe staystrong staythin subscribe togetherwecan
Mental Health	abuse addiction anxiety anxietyattack anxious bd bdp bipolar bipolar disorder borderlinepersonality borderlinepersonalitydisorder counseling crazy disorder	inpatient insane insecure insomnia mental mentaldisorder mentalhealth mentalillness ocd outpatient panic panicattack panicdisorder paranoia	psycho psychopath psychosis psychotic psychward ptsd schizophrenia sick socialanxiety therapy trauma voices
Self Injury	blood bruises burn burning cat catscratch cut cuts	cutter cutting deepcuts hurt razor scar scarred scars	scratching selfharm selfharming selfharmmm selfharmmmm selfharmmmmm selfinjury

Suicide/Ideation	dead	hanged	overdose
	deadinside	intiredofliving	pill
	death	iwanttodie	pills
	demon	kill	sue
	die	killme	suicide
	done	killmyself	suicidal
	drowning	knife	wannadie
	dying	letgo	
	gun	noonewouldnotice	
Weight	66kg	massive	thin
	adizero	obesity	thin15
	bbw	scale	thyn
	beskinny	scales	tiny
	big	size0	toofat
	chunky	size00	weight
	fat	sizecero	weightgain
	fatty	sizezero	weightloss
	fatwhale	skinny	whale
	huge	skinnymale	
	loseweight	skinnymosta	

APPENDIX B. SURVEY TOOLS

B.1 Technology Survey

Demographics

1. How old are you (in years)?

2. What gender do you most identify with?

☐ Female

☐ Male

☐ Other

☐ Decline to answer

3. What is your zip code?

4. What is your Ethnicity?

☐ Hispanic or Latino

☐ Not Hispanic or Latino

☐ Decline to Answer

5. What race do you most identify with?

☐ American Indian or Alaska native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander

☐ White or Caucasian

☐ Other

☐ Decline to Answer

Access to Technology

6. Do you have a computer at home?

☐ Yes

☐ No

7. If yes, can you access the Internet from your home computer?

☐ Yes

☐ No

8. Do you use a computer at school?

☐ Yes

☐ No

9. If yes, are you allowed to use the Internet from the school computer?

☐ Yes

☐ No

10. Do you have a mobile phone?

☐ Yes

☐ No

11. If yes, is it a smart phone?

☐ Yes

☐ No

12. If yes, can you access the Internet from your phone?

☐ Yes

☐ No

13. If you have a mobile phone, do you use your phone for (CHECK ALL THAT APPLY)

☐ Text Messaging

☐ Internet Surfing

☐ Photo sharing

☐ Video Sharing

☐ Audio Sharing

☐ Listening to Audio

☐ Watching Video

☐ Playing Games

14. When going online, which technology do you use the most?

- ☐ Computer (desktop or laptop)
- ☐ Tablet (e.g. iPad, Surface)
- ☐ Mobile/Smartphone

15. Where do you use a computer the most?

- ☐ School
- ☐ Home

Other (please specify)

16. When I am not with them, I talk to my friends most using:

- ☐ Text messages
- ☐ Email
- ☐ Phone calls
- ☐ Online Sites (e.g. Snapchat, Instagram)

Social Media Use

17. Do you regularly visit any of the social media platforms below? (Check all that apply)

- ☐ Facebook
- ☐ Instagram
- ☐ Oovoo
- ☐ Tumblr
- ☐ YikYak
- ☐ Reddit
- ☐ YouTube
- ☐ Twitter
- ☐ Digg
- ☐ Keek
- ☐ Kik
- ☐ Pinterest
- ☐ Flickr
- ☐ Bebo
- ☐ Periscope
- ☐ Snapchat
- ☐ VK
- ☐ Google+
- ☐ Ask.fm
- ☐ LiveJournal
- ☐ MySpace
- ☐ Slack
- ☐ Other (please specify)

18. Do you use social networking sites for any of the following activities? (Check all that apply)

- ☐ Keep in touch with relatives
- ☐ Keep in touch with friends who live far away
- ☐ Talk to friends from school, church, sports teams, etc.
- ☐ Download photos and/or videos other people upload
- ☐ Upload your own photos and/or videos
- ☐ Comment on blogs/news posts/recommender sites

Online Influences

19. Through your interactions with friends or others online have you ever:(check all that apply)

- ☐ Been influence to buy something, wear something, or go somewhere
- ☐ Tried to get someone else to buy something, wear something, or go somewhere
- ☐ Felt pressured to share something that you normally would not (info, videos, photos)
- ☐ Been pressured or influenced on who you could be friends with
- ☐ Been pressured on how to treat someone at school or elsewhere
- ☐ Tried to pressure or influence how someone else treated someone at school or elsewhere

20. Have you ever felt bullied through texting or other online activities?

- ☐ Yes
- ☐ No

21. If you have, did you feel bullied by (check all that apply):

- ☐ Someone you knew
- ☐ Someone you didn't know
- ☐ Decline to answer

22. Do you think of your online self (who you are or who you act like) as different from your real-world self?

- ☐ Yes
- ☐ No
- ☐ I don't know

23. Do you think your online presence more often reflects your real self or are you playing a role?

- ☐ Reflects the real me
- ☐ I'm playing a role
- ☐ I don't know
- ☐ Decline to answer

24. If "Yes", how are you different online?

25. Have you ever used social media to look up content related to extreme weight loss or eating disorder-related content?

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ Decline to Answer

26. Have you ever posted content online that could be considered thinspiration or related to eating disordered behavior?

- ☐ Yes
- ☐ No
- ☐ Decline to answer

27. If you do engage in eating disordered content online, what social networks or online communities do you use to consume or share content?

28. If you do engage in eating disordered content online, do you have separate social media accounts for that activity?

- ☐ Yes
- ☐ No
- ☐ Decline to answer

29. Has a parent, caregiver, or healthcare provider ever asked about your eating disordered activity online?

- ☐ Yes
- ☐ No
- ☐ Decline to answer

30. If you look up eating disordered content online, do you ever feel influenced by what you are seeing?

- ☐ No
- ☐ Yes (please specify how you felt influenced)

B.2 Medical Outcomes Survey

1. In general, would you say your health is:

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

2. Compared to one year ago, your health is:

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than a mile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Cut down the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>
Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/>	<input type="radio"/>

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
Cut down the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>
Didn't do work or other activities as carefully as usual	<input type="radio"/>	<input type="radio"/>

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

7. How much bodily pain have you had during the past 4 weeks?

- ☐ None
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all
- ☐ A little bit
- ☐ moderately
- ☐ Quite a bit
- ☐ Extremely

9. How much of the time during the past 4 weeks:

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been a very nervous person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been a happy person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
☐ Most of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

11. How TRUE or FALSE is each of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. Over the last two weeks, how often have you been bothered by the following problems?

	Not at all	Several Days	More than half the days	Nearly every day
Feeling feverous, anxious, or on edge:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to stop or control worrying:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Little interest or pleasure in doing things:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX C. PARTICIPANT ENGAGEMENT GUIDES

C.1 Patient Interview Guide

1. Can you please state your name?
2. How long have you been dealing with your eating disorder?
3. Can you tell me about your eating disorder?
 - What are your symptoms?
 - How severe are they?
 - How often do you actively battle these symptoms?
4. Do you have someone that you talk to about your eating disorder? That gives you support?
 - [if not family] How did you meet this person?
5. Can you talk to me about the medical help/interventions that you have received?
 - How many health professionals have you seen?
 - How effective were these?
 - What has helped you the most?
6. Have you ever encountered eating disordered content or activities online? Can you describe them?
7. Did social media play a role in your eating disorder? If so, can you explain how?
 - Do you continue to access eating disordered social media content while in treatment? After treatment?
 - Were there specific hashtags you used?
8. Do you feel comfortable talking to your family about your eating disorder? If so, how so?
9. Do you think social media platforms should intervene when people are searching for or posting about eating disorders? Why?
10. What has been the impact on you? Your family?

C.2 Healthcare Provider Interview Guide

1. Can you please state your name?
2. What is your profession?
3. How many years have you been in that profession?
4. Do you currently have patients who engage in eating disordered behaviors or have clinically diagnosed eating disorders?
 - If so, how many patients with these behaviors do you estimate are in your care?
 - What type of eating disordered behaviors do you typically see?
5. Please explain your process for deducing the extent, scope, and influences that go into a new patient who comes into your care.
 - Do you use validated instruments?
 - Is this process similar across patients with different types of eating disorders?
6. What are the most common influences that you see present with your patients?
7. Do your patients talk about their online activity with you?
8. What role does social media play in your patient's disease?
 - If affirmatively answered, what tools do you use to ascertain this information?
9. What type of disordered behavior would you expect to see online?
10. What web platforms are routinely used for online disordered behaviors?
11. If social media does play a role in your patients' disease, how do you factor this into the stages of treatment? Diagnosis, Acute treatment, Ongoing treatment?

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